World Health Organization

# WHO Guidance on Research Methods for Health Emergency and Disaster Risk Management

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# Contents

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# Abbreviations

| | |
|---|---|
| ALNAP | Active Learning Network for Accountability and Performance |
| AMBs | agent-based models |
| APOP trial | Attenuating Post-traumatic distress with Omega-3 Polyunsaturated fatty acid trial |
| AI | artificial intelligence |
| CART | communities advancing resilience toolkit |
| CBPR | community-based participatory research |
| CCOUC | Collaborating Centre for Oxford University and Chinese University of Hong Kong for Disaster and Medical Humanitarian Response |
| CDC | Centers for Disease Control and Prevention |
| CDSR | Cochrane Database of Systematic Reviews |
| CEBaP | Centre for Evidence-based Practice |
| CIOMS | Council for International Organizations |
| CRED | Centre for Research on the Epidemiology of Disasters |
| CRASH trial | Corticosteroid Randomisation After Serious Head Injury trial |
| CUHK | Chinese University of Hong Kong |
| DALY | disability-adjusted life year |
| DATASUS | Departamento de Informática do SUS |
| DFID | Department for International Development |
| DHEAT | disaster health emergencies assistance team |
| DLNM | distributed lagged non-linear model |
| DMAT | disaster medical assistance team |
| DPAT | disaster psychiatric assistance team |
| DRR | disaster risk reduction |
| E4GDH | evidence for global and disaster health |
| EAI | emergency access initiative |
| ECC | Environment, Conflict and Cooperation |
| ED | emergency department |
| EVD | Ebola virus disease |
| EDRM | emergency and disaster risk management |
| ELRHA | Enhancing Learning and Research for Humanitarian Assistance |
| EM-DAT | emergency events database |
| EMIS | emergency medical information system |

| | |
|---|---|
| EMT | emergency medical team |
| EnRiCH | Enhancing Resilience and Capacity for Health |
| ERIC | Education Resources Information Center |
| EWARS | Early Warning, Alert and Response System |
| FA | factor analysis |
| FARC | revolutionary armed forces of Colombia |
| FFS | farmer field schools |
| GBD | Global Burden of Disease |
| GBV | gender-based sexual violence |
| GIS | geographic information system |
| GRADE | Grading of Recommendations, Development and Evaluation |
| Health EDRM | Health Emergency and Disaster Risk Management |
| HELP | Humanitarian Evaluation, Learning and Performance |
| HHA | Humanitarian Health Action |
| HIV | human immunodeficiency virus |
| HINARI | Health Inter-Network Access to Research Initiative |
| HPV | human papilloma virus |
| IADL | instrumental activities for daily living |
| IASC | Inter-Agency Standing Committee |
| ICD | International Statistical Classification of Diseases and Related Health Problems |
| ICN | International Council of Nurses |
| IDI | integrated data infrastructure |
| IDP | internally displaced person |
| IFLA | International Federation of Library Associations and Institutions |
| IHME | Institute for Health Metrics and Evaluation |
| IOM | International Organization of Migration |
| ITS | interrupted time series |
| IRC | International Rescue Committee |
| IV | instrumental variable |
| JBI SUMARI | Joanna Briggs Institute’s System for Unified Management, Assessment and Review of Information |
| JNA | Japanese Nursing Association |
| JRAT | Japanese Disaster Rehabilitation Assistance Team |
| J-SPEED | Japanese version of Surveillance in Post Extreme Emergency and Disaster |
| KAP | knowledge, attitude and practice |
| LGBTQI | lesbian, gay, bisexual, transgender, queer, and intersex |
| LILACS | Latin American and Caribbean Health Sciences Literature database |

| | |
|---|---|
| LMICs | low- and middle-income countries |
| MAM | moderate-acute malnutrition |
| MCDA | multi-criteria decision analysis |
| MEXT | Ministry of Education, Culture, Sports, Science and Technology (Japan) |
| MHLW | Ministry of Health, Labour and Welfare (Japan) |
| MHPSS | mental health and psychosocial support |
| MIRA | Multi-Cluster/Sector Initial Rapid Assessment |
| MDS | minimum data set |
| M&E | monitoring and evaluation |
| NET | narrative exposure therapy |
| NGO | nongovernmental organization |
| OLS | ordinary least squares |
| PAHO | Pan American Health Organization |
| PAR | participatory action research |
| PBS | poverty benefit scheme |
| PCA | principal components analysis |
| PFA | psychological first aid |
| PHEP | public health emergency preparedness |
| PRECEDE-PROCEED | Predisposing, Reinforcing, and Enabling Constructs in Educational/Environmental Diagnosis and Evaluation-Policy, Regulatory, and Organizational Constructs in Educational and Environmental Development |
| PRISMA | Preferred Reporting Items for Systematic Reviews and Meta-Analyses |
| PROGRESS PLUS | Place of residence; Race/ethnicity/culture/language; Occupation; Gender/sex; Religion; Education; Socioeconomic status; Social capital. Personal characteristics associated with discrimination; Features of relationships; Time-dependent relationships |
| PSM | propensity score matching |
| PTSD | post-traumatic stress disorder |
| QALY | quality-adjusted life-year |
| QED | quasi-experimental design |
| RDD | Regression discontinuity design |
| REC | research ethics committee |
| RECORD | Reporting of studies Conducted using Observational Routinely collected health Data |
| REPRISE | Reporting guideline for Priority Setting of health research |
| SAR | Special Administrative Region |
| SCU | staging care unit |
| SDGs | Sustainable Development Goals |
| SIMOP | simulation optimization |

| | |
|---|---|
| SMS | short message service |
| SNOMED-CT | systematized nomenclature of medicine clinical terms |
| SPEED | Surveillance in Post Extreme Emergency and Disaster (system) |
| SPICE | setting, perspective/population, intervention, comparison and evaluation |
| SRDR | Systematic Review Data Repository |
| SWAT | study within a trial |
| TRIP | Turning Research into Practice |
| UCDP | Uppsala Conflict Data Program |
| UK | United Kingdom of Great Britain and Northern Ireland / United Kingdom |
| UHC | Universal Health Coverage |
| UN | United Nations |
| UNDP | United Nations Development Programme |
| UNDRR | United Nations Office for Disaster Risk Reduction |
| UNESCO | United Nations Educational, Scientific and Cultural Organization |
| UNHCR | United Nations High Commissioner for Refugees |
| UNICEF | United Nations Children's Fund |
| UNISDR | United Nations International Strategy for Disaster Reduction (current UNDRR) |
| USA | United States of America |
| WASH | water, sanitation and hygiene |
| WHE | World Health Organization Health Emergencies Programme |
| WHO | World Health Organization |
| WTC | World Trade Center |
| YLD | years lost due to disability |
| YLL | years of life lost |

# Glossary

| Term | Definition |
|---|---|
| **"explode" search** | Exploding a search term means that the search will retrieve all references indexed to that term, as well as all references indexed to any narrower terms. |
| **7P framework** | Framework to help identify relevant stakeholders: (1) patients and the public; (2) providers; (3) purchasers; (4) payers; (5) policy makers; (6) product makers; and (7) principal investigators. |
| **active surveillance** | Closely watching a patient or population but without giving any intervention unless their condition worsens. |
| **activities of daily living (ADL)** | Things normally done in daily living, including any activity for self-care such as feeding, bathing, dressing, grooming, work, homemaking and leisure. |
| **adaptability** | Ability of a person or population to change their actions, course or approach to doing things in order to suit a new situation. |
| **advocacy** | Public support for or recommendation of a particular cause or policy. |
| **advocacy research** | Research that is conducted with the intention of providing evidence and arguments that can be used to support a particular cause or position. |
| **agent-based model** | Class of computational model for simulating the actions and interactions of autonomous agents (both individual or collective entities such as organizations or groups) with a view to assessing their effects on the system as a whole. |
| **age-specific mortality rate** | Mortality rate for a particular age group (calculated as the number of deaths in the age group divided by the number of persons in that age group). |
| **All Right? campaign** | Health-promoting social marketing campaign based in Ōtautahi, Christchurch, New Zealand. |
| **all-hazards approach** | An approach to the management of the entire spectrum of emergency risks and events based on the recognition that there are common elements (and common capacities required) in the management of these risks, including in the responses to virtually all emergencies. |

| Term | Definition |
|---|---|
| **allocation concealment** | Technique used to prevent selection bias in randomized trials by concealing information about which group a participant will be assigned to until after the participants have joined the trial. |
| **antigenicity-stability fitness model** | Computational model that estimates the fitness (that is expected growth rate) of viral clade. |
| **artificial intelligence (AI)** | The use of computer systems to correctly interpret external data, to learn from it, and to use those learnings to achieve specific goals and tasks. |
| **asset lens** | A viewpoint which examines a situation, person, group or organization in terms of its (their) positive attributes or assets which could contribute to a solution. The opposite of an asset lens is a deficit-oriented lens which focuses on problems and limitations. |
| **asset literacy** | Consists of four components which include: 1) an understanding of what assets are; 2) the potential contribution of different assets; 3) the extent to which people know how to mobilize or access different types of assets; and 4) possessing self-efficacy and motivation to move from awareness to taking action. |
| **asset mapping** | Process of identifying resources and assets within a community to understand its strengths and opportunities which can contribute to resilience and community development. |
| **asset-based approach** | An orientation toward looking at a situation or issue in terms of potential resources that can contribute to a solution, or existing systems and structures that can be built on to improve a situation or address the problem. The opposite of an asset-oriented approach is a deficit-oriented approach, which looks at situations or issues in term of vulnerabilities, limitations, problems, or liabilities. |
| **attack rate** | Percentage of the population that contracts the disease in an at-risk population during a specified time period. |
| **autoethnography** | Form of qualitative research in which an author uses self-reflection and writing to explore anecdotal and personal experience and connect this autobiographical story to wider cultural, political, and social meanings and understandings. |
| **axial coding** | Technique in qualitative research that involves relating data together in order to reveal codes, categories, and subcategories ground within participants' voices within one's collected data. |
| **Bayesian network** | Type of probabilistic graphical model that uses Bayesian inference for probability computations. |

| Term | Definition |
|---|---|
| **behavioural change theories** | Attempts to explain why behaviours change. |
| **benchmarks** | Standards or reference values for indicators that serve as signposts to let the researcher, or other interested people such as policy makers, know what has been achieved or how severe a situation is. |
| **bias** | Distortion in the data that can lead to conclusions that are systematically incorrect. |
| **big data** | Extremely large datasets that may be analysed to reveal patterns, trends, and associations (for example, in relation to human behaviour and interactions). |
| **blinding** | Process of keeping a person's study-group assignment hidden after allocation to minimize bias. |
| **blocked randomization** | Method used in randomized trials to ensure that participants with specific characteristics are assigned to different interventions with equal probability. |
| **Body Mass Index (BMI)** | Person's weight in kilograms divided by their height in meters squared. |
| **bracketing** | Method used in qualitative research to mitigate the potentially deleterious effects of preconceptions that may lead to bias. |
| **burden of disease** | Impact of a health problem on, for instance, financial cost, mortality, morbidity, or other indicators. |
| **caliper matching** | Technique in which comparison units within a certain width of the propensity score of the intervention units get matched (the width is generally a fraction of the standard deviation of the propensity score) |
| **Call Data Records (CDR)** | A call data record – also known as a call detail record – (CDR) provides information about calls made over a phone service. A CDR report contains information related to a telephone call, such as the origin, destination, duration and network. |
| **case fatality rate** | A measure of the severity of a disease and defined as the proportion of cases of a specified disease or condition which are fatal within a specified time. |
| **case series** | Study that tracks people with a known exposure to determine their outcomes. |
| **case study** | Process or record of research for a particular person, population or situation. |

| Term | Definition |
|---|---|
| **case-control study** | Study in which the effect of an exposure is measured by comparing the history of exposure between cases (for example, individuals who have – or die of – the disease) and controls (individuals without – or who do not die of– the disease). |
| **categorical data** | Data that can take one of a limited number of values. |
| **cause-specific mortality rate** | Mortality rate from a particular cause of death (calculated as the number of deaths from a particular cause divided by the number of persons in the population). |
| **chi-square test** | Statistical test that measures how expected data compares to observed data. |
| **circumstantial data** | Data on aspects of the circumstances of a person or population that may affect the wider determinants of health, including socio-economic, lifestyle and environmental data. |
| **citizen science** | Scientific research conducted, either in whole or in part, by amateur (that is nonprofessional) scientists. |
| **clade** | Group of organisms that can be evolutionarily traced back to a common ancestor. |
| **cluster randomized trial** | Randomized trial in which the unit of allocation is a group of people, rather than an individual. |
| **cluster sampling** | Technique in which potential participants in a study are first assigned to groups (clusters) and the participants are then randomly chosen from within those groups. |
| **coarsened exact matching** | Statistical matching technique which temporarily coarsens the data according to the researcher's ideas (for example, the use of coarse age groups rather than exact birth dates). |
| **Cochrane Database of Systematic Reviews (CDSR)** | Online journal/database published by Cochrane (formerly the Cochrane Collaboration) containing Cochrane Reviews and the protocols for these. |
| **Cochrane Review** | Systematic review published in the Cochrane Database of Systematic Reviews. |
| **coding grid** | Otherwise known as a coding scheme, this is an organization system for grouping coding labels or categories that will be used to code qualitative data. |
| **cognitive bias** | Systematic deviation from norm or rationality in judgment when individuals create their own "subjective reality" from their own perceptions. |

| Term | Definition |
|---|---|
| **cohort study** | Study of a group (cohort) defined by exposure characteristics or a process of recruitment. Outcomes are ascertained and compared in all members of the cohort. |
| **cold-chain** | Temperature-controlled supply chain |
| **collective action model** | A socio-ecological approach that takes account of the interrelationship between the individual and the environment. The collective action model is based on the view that health is determined largely by factors that operate outside the control of individuals. |
| **collective case** | An approach to case study research in which the researcher compares multiple cases (bounded systems) to explore an issue. |
| **collective intelligence** | Shared or group intelligence that emerges from the collaboration, collective efforts, and competition of many individuals. |
| **community level assessment** | Assessment of disaster risks at the level of the community. |
| **community-based participatory research (CBPR)** | A participatory approach to research that focuses on creating social change with a community through collaborative partnerships and shared decision-making. |
| **community-led research (CLR)** | Often used interchangeably with community-based participatory research (CBPR). |
| **complexity theory** | Study of complexity and of complex systems. |
| **composite index** | Index extracting common trends across many variables, which is useful to illustrate complex and elusive issues. |
| **conceptual framework** | Analytical tool with several variations and contexts, which can be applied in different categories of work where an overall picture is needed. |
| **confidence interval** | Statistical measure of precision for an estimate of a population parameter. Various levels of confidence in the point estimate can be defined, but the 95% confidence interval is commonly used. The interval shows the range of values in which the true value of a parameter should occur 95 times out of 100 if the population of interest is sampled repeatedly. |
| **confounder** | Source of error in interpretation, which occurs when the effect of an exposure on an outcome is affected by another exposure, which is correlated with the first exposure. |
| **CONSORT** | Guideline for the reporting of randomized trials. |

| Term | Definition |
|---|---|
| **contact tracing** | The identification and follow-up of persons who may have come into contact with an infected person or infectious materials. |
| **continuous data** | Data that can take any value within a range. |
| **control chart** | Graph used to study how a process changes over time. |
| **controlled before-after study** | Study in which outcomes are measured before and after an intervention in a group that receives it and in another group that does not receive the intervention. |
| **convenience sampling** | Type of non-probability sampling method where the sample is taken from a group of people who are easy to contact or reach. |
| **core outcome set** | Agreed standardized set of outcomes that should be measured and reported, as a minimum, in research in a specific topic area. |
| **cost-benefit analysis** | Technique used to calculate a cost-benefit ratio or measure of net-benefit (benefits minus costs). |
| **cost-benefit ratio** | Indicator showing the relationship between the relative costs and benefits of a proposed intervention or project. |
| **cost-consequence analysis** | Technique used to compare costs and outcomes by placing them in discrete categories. |
| **cost-effectiveness analysis** | Technique used to compares costs measured in monetary terms with outcomes measured in natural units. |
| **cost-minimization analysis** | Technique used to compare interventions based on costs measured in monetary terms. |
| **cost-utility analysis** | Technique used to compare costs measured in monetary terms with consequences measured via a measure of health gain or utility. |
| **counterfactual** | Hypothesis about what outcomes would have happened without the action being studied. |
| **CRED** | Centre for Research on the Epidemiology of Disasters is a research unit of the University of Louvain, Belgium. |
| **critical appraisal** | Process for carefully and systematically examining research to judge its trustworthiness, value and relevance. |
| **critical ethnography** | An approach to ethnography (the study of social behaviours of a culture-sharing group) that includes advocacy for marginalized populations, studying issues of inequality, power, and repression. |

| Term | Definition |
|---|---|
| **cross-sectional study** | Observational study that analyses data from a population or a subset at a specific point in time. |
| **crowd creation** | A form of crowdsourcing that uses large numbers of people to co-create (such as Threadless). |
| **crowd processing** | A form of crowdsourcing that uses large numbers of people to process information independently, which become partially aggregated for quality assurance (such as ReCAPTCHA). |
| **crowd rating** | A form of crowdsourcing that uses large numbers of people to vote or provide their opinion (for example, TripAdvisor or Hollywood Stock Exchange). |
| **crowd solving** | A form of crowdsourcing that uses a large numbers of people to solve a problem, where the best submission is the 'winner' (such as FoldIt). |
| **crowdsourcing** | A method to harness the knowledge, creativity, or sheer manpower of a large number of people at once and can achieve this through crowd creation, crowd processing, crowd rating, or crowd solving. |
| **crude birth rate** | Rate of births in a population, calculated as the number of live births multiplied by 1000, divided by the number of people in the mid-interval population. |
| **crude growth rate** | Growth in a population, calculated as the crude birth rate minus the crude mortality rate. |
| **crude mortality rate (CMR)** | Rate of deaths in a population, calculated as the number of deaths multiplied by 1000, divided by the number of people in the mid-interval population. |
| **curse of dimensionality** | Modelling tasks get exponentially harder as the dataset contains too many variables. |
| **Data and Safety Monitoring Board** | Independent group of experts who monitor patient safety and treatment effects while a clinical trial is ongoing. |
| **data dictionary** | Set of information describing the contents, format, and structure of a database and the relationship between its elements. |
| **data mining** | Practice of generating new information by examining large pre-existing databases. |
| **data revolution** | The large increase in the volume and types of data that are currently collected by governments, private companies, NGOs, researchers and citizens. |
| **deductive research** | Technique for testing a hypothesis based on existing theory. |

| Term | Definition |
|---|---|
| **deficit-based approach** | An orientation toward looking at a situation or issue in terms of vulnerabilities, limitations, problems, or liabilities. The opposite of a deficit-oriented approach is an asset-oriented approach which looks at situations or issues in terms of potential resources that can contribute to a solution or existing systems and structures that can be built on to improve a situation or address the problem. |
| **Delphi study** | Technique using a panel of experts to reach a consensus. |
| **demographic data** | Data to describe the characteristics of a population (such as age, gender and socio-economic status). |
| **dependent variable** | Variable whose value depends on that of another variable. |
| **Desinventar** | Tool for generating National Disaster Inventories and constructing databases of damage, losses and effects of disasters. |
| **dialogic/performance analysis** | An analytic strategy in narrative research that views narratives as co-constructed. Analysis involves interpreting the story, the context of the story, who is telling the story, and who is the intended audience for the story. |
| **dichotomous data** | Data that can take one of two values. |
| **Difference-in-differences** | Statistical technique that analyses the differential effect of an intervention and a comparator. |
| **Digital Elevation Model (DEM)** | 3D representation of terrain. |
| **dimension reduction method** | Explain a multivariate dataset using a smaller number of dimensions than the original one. |
| **direct costs** | Price that can be directly tied to the production of a specific item or service. |
| **directly affected** | People who have suffered injury, illness or other health effects; who were evacuated, displaced or relocated or have suffered direct damage to their livelihoods, economic, physical, social, cultural and environmental assets (United Nations General Assembly 2017). |
| **disability-adjusted life year (DALY)** | Population metric of life years lost to disease due to both morbidity and mortality. |

| Term | Definition |
|---|---|
| **disaster** | A serious disruption of the functioning of a community or a society at any scale due to hazardous events interacting with conditions of exposure, vulnerability and capacity, leading to one or more of the following: human, material, economic and environmental losses and impacts. |
| **Disaster Health Emergencies Assistance Team (DHEAT)** | Team that assist with management of the public health sector in local municipalities affected by a disaster, through information collection, integration, analysis and sharing with fieldworkers. |
| **Disaster Medical Assistance Team (DMAT)** | Specially trained medical professional teams comprising up to five members, including medical doctors, nurses and logisticians, who are able to work together using a single car. |
| **disaster medical coordinator** | Person officially assigned by a prefecture to coordinate the activities of external and internal medical assistance teams. |
| **Disaster Psychiatry Assistance Team (DPAT)** | Team to assist psychiatric hospitals and support surge mental health needs in areas affected by a disaster by assessing local psychiatric needs, and collaborating with DMAT and other assistance teams and local psychiatric facilities to provide high quality psychiatric medicine. |
| **disaster risk** | The potential loss of life, injury, or destroyed or damaged assets which could occur to a system, society or a community in a specific period of time, determined probabilistically as a function of hazard, exposure, vulnerability and capacity. |
| **disaster risk reduction** | Aactivities aimed at preventing new and reducing existing disaster risk and managing residual risk, all of which contribute to strengthening resilience and therefore to the achievement of sustainable development. |
| **discount rate** | Rate by which a given estimate is "discounted" over time to account for the tendency of individuals to place a lower value on a cost or consequence that occurs in the future, compared to one that occurs immediately—such as receiving a health or financial benefit now versus one of similar value five years in the future. |
| **discounting** | Technique in economic analysis in which a lower value is placed on a future cost or consequence compared to an immediate one. |
| **disruption** | A disturbance or interruption to social order. |

| Term | Definition |
|---|---|
| **Distributed Lagged Non-linear Model (DLNM)** | A modelling framework that can simultaneously represent non-linear exposure–response dependencies and delayed effects. |
| **dynamic context** | An everchanging environment in which complex adaptive systems operate. |
| **dynamic social contact network** | Mathematical model that can be used to explain and predict the spread of infectious diseases with the consideration of social contact patterns. |
| **Early Warning, Alert and Response System (EWARS)** | The organized mechanism to detect as early as possible any abnormal occurrence or any divergence from the usual or normally observed frequency of phenomena. |
| **ecological fallacy** | Misinterpretation of statistical data that occurs when inferences about the nature of individuals are deduced from inferences about the group to which they belong. |
| **ecological study** | Study of the effects of risk-modifying factors on outcomes based on populations that are defined geographically or by time period. |
| **economic evaluation** | Structured way to evaluate costs and consequences of a programme or policy compared with an alternative course of action. |
| **economic impact study** | Study that quantifies the costs and consequences of past or potential events. |
| **effectiveness trial** | Study to determine the effects of an intervention when used in routine practice. |
| **efficacy trial** | Study to determine the effects of an intervention under ideal circumstances. |
| **electronic bibliographic databases** | Online sources of scientific literature. |
| **EM-DAT** | Emergency Events Database, which is a free, searchable database of data on disasters, produced by CRED. |
| **Emergency Medical Information System (EMIS)** | System used to share real-time information among fieldworkers, headquarters and central government during a disaster. |
| **emergency medical team** | Groups of health professionals (doctors, nurses, paramedics, and so on) that treat patients affected by an emergency or disaster. |
| **Emergency Preparedness Resource Inventory** | Online tool that can assess the regional supply of critical resources, prepare for incident response, identify deficiencies in services, and support resource acquisition decisions. |
| **emic perspective** | A person's own perspective of reality. |

| Term | Definition |
|---|---|
| **empowerment** | A process to make decision-making accessible to populations that are oppressed. This also involves processes that support individuals to see themselves as able and entitled to contribute to decision-making. |
| **endogeneity problem** | Problem that arises when something is related to both the dependent and the independent variable. |
| **endogenous switching regression** | Technique which allows tests of assumptions about the exogeneity of intervention effects. |
| **epistemological** | Relating to the theory of knowledge, especially with regard to its methods, validity, and scope, and the distinction between justified belief and opinion. |
| **Epitope** | Part of an antigen that is recognized by the immune system. |
| **equifinality** | Property of allowing or having the same effect or result from different events. |
| **ethical review committee** | An independent group that oversees the ethical aspects of a research study. |
| **ethnography** | Scientific description of peoples and cultures with their customs, habits, and mutual differences. |
| **ethnomethodology** | Sociological analysis that examines how individuals use everyday conversation to construct a common-sense view of the world. |
| **etic scientific perspective** | An external, social scientific perspective on reality. |
| **Euclidean distances** | Measure of dissimilarity, which is a straight-line distance in the Euclidean space. |
| **evidence gap map** | Thematic evidence collection for a particular topic which can be used to identify key gaps in the evidence base which might require new research. |
| **excludability** | In an experiment setting, such as a randomized trial or natural experiment, the excludability assumption means that the effects of an exposure or intervention on the outcome depend only on the exposure or intervention itself and not on other features of the experiment. For example, the excludability assumption can be violated if there are asymmetries in intervention group measurements, for instance because of a faulty or miscalibrated instrument being used more frequently in one group than another. |
| **experimental research** | Research in which the researcher intervenes to change something and to study the effects of that change. |
| **explanatory trial** | Study to determine the effects of an intervention under ideal circumstances. |

| Term | Definition |
|---|---|
| **exposome** | Measure of all the exposures of an individual during their life and how these relate to their health. |
| **ex-post single difference** | Comparison in the outcome for an intervention group after the intervention to its baseline value. |
| **exposure** | 1. The situation of people, infrastructure, housing, production capacities and other tangible assets located in hazard-prone areas; 2. contact of a chemical, physical or biological agent with the outer boundary of an organism (for example, through inhalation, ingestion or dermal [skin] contact). |
| **external validity** | Extent to which a study can be generalized to other situations. |
| **facilities and administrative costs** | Costs needed to implement daily activities which are not directly a part of the project's primary outcome, such as accounting and information technology. Also referred to as overhead costs. |
| **factor analysis** | To explain the covariances or correlations of the observed variables by means of a few common factors. |
| **FAIR principles of data sharing** | Principles that state all data should be Findable, Accessible, Interoperable and Resuable. |
| **farmer field school** | Group-based learning process that has been used by a number of governments, NGOs, and international agencies to promote integrated pest management. |
| **feasibility** | How easy it is to implement the intervention and its related research. |
| **feedback loop** | Interconnected loops within a complex adaptive system that provide regulatory information to other components of the system; feedback can be positive or negative. |
| **feng shui** | A Chinese system of laws considered to govern spatial arrangement and orientation in relation to the flow of energy (chi), which are taken into account when siting and designing buildings. |
| **field notes** | Notes taken by a researcher while conducting their research. |
| **fixed effects model** | Statistical model in which the model parameters are fixed or non-random quantities. |
| **flexible spline functions** | Functions that are defined piecewise by polynomials. |
| **focus group** | Group of people assembled to discuss a particular topic. |
| **forest plot** | Graphical display of estimated results from a series of studies along with an overall estimate. |

| Term | Definition |
|---|---|
| **formative evaluation** | Evaluation conducted while a programme is in progress, mainly for improving implementational details. |
| **Fourier terms** | Set of orthogonal trigonometric functions (sine and cosine) used to approximate data. |
| **Gantt chart** | Bar chart that illustrates a project schedule. |
| **gatekeeper** | Person controlling access to a population. |
| **gatekeeper bias** | A prejudice that may occur when recruitment is affected by those who connect researchers with potential respondents. |
| **genealogical tree** | Record of ancestry and descent. |
| **generalizability** | Extent to which the findings of a study can be applied in other situations. |
| **generalized linear model** | Flexible generalization of ordinary linear regression that allows for response variables that have error distribution models other than a normal distribution. |
| **geographic information systems** | A computer system that incorporates hardware, software, and infrastructure for capturing, manipulating, integrating, interrogating, modelling, analysing, and visualizing all forms of geographically referenced information. |
| **Glaserian grounded theory** | A less structured approach to grounded theory (qualitative research methodology that generates theory grounded in data) that uses active coding in data analysis. |
| **Global Burden of Disease (GBD) Study** | Regional and global research programme of disease burden that assesses mortality and disability from major diseases, injuries and risk factors. |
| **Grading of Recommendations, Development and Evaluation (GRADE)** | Methodology to grade the quality of evidence and strength of recommendations in guidelines. |
| **grey literature** | Documents produced by organizations outside of the traditional commercial or academic publishing and distribution channels. |
| **grounded theory** | Methodology used to construct theories through methodical gathering and analysis of data, using inductive reasoning. |
| **guided discovery** | A teaching and learning environment allowing active participation in the discovery of knowledge. |
| **haemagglutinin** | Glycoproteins that cause red blood cells to clump together. |

| Term | Definition |
|---|---|
| **hard-to-reach group** | Group of people that is typically under-represented in the planning process or has limited capacity for involvement. |
| **Harvard style** | Citation style used in documents, in which partial citations (Smith 2010, for example) are enclosed in parentheses and embedded in the text and the citations are listed in alphabetic order by surname of the first author. |
| **hazard** | 1. A process, phenomenon or human activity that may cause loss of life, injury or other health impacts, property damage, social and economic disruption or environmental degradation; 2. Source of potential harm. |
| **hazmat suit** | Personal protective equipment that consists of an impermeable whole-body garment worn as protection against hazardous materials. |
| **Health Belief Model (HBM)** | Social psychological health behaviour change model for explaining and predicting health-related behaviours, particularly in relation to the uptake of healthcare services. |
| **Health Emergency and Disaster Risk Management (Health-EDRM)** | The systematic analysis and management of health risks, posed by actual or potential hazardous events, including emergencies and disasters, through a combination of hazard, exposure and vulnerability reduction to prevent and mitigate risks, preparedness, response, and recovery. |
| **health event data** | Data such as the registration of births and deaths, diseases, self-reported health and health activity. |
| **Health Vulnerability Index** | Index to indicate the health vulnerability of the countries along the Belt and Road Initiative, including three latent factors, namely population status, disease prevention and coping capacity. |
| **Heat Vulnerability Index** | Index to indicate the heat vulnerability of areas in London, including nine variables, which are households in rented tenure, households in a flat, population density (persons/hectare), households without central heating, population above 65 years old, population with self-reported health status, receiving any kind of social benefit, single pensioner households and ethnic group. |
| **Heckman sample selection model** | Method for estimating regression models which suffer from sample selection bias. |
| **impact factor** | Scientometric value that shows the yearly average number of citations for articles published in a journal in the last two years. |

| Term | Definition |
|---|---|
| **incidence** | The number of instances (rate of occurrence) of illness commencing, or of persons falling ill during a given period in a specified population, thus conveying information about the risk of contracting a disease. |
| **incidence rate ratio** | Ratio of two incidence rates. |
| **incidence-based YLD** | Population metric of life years lost due to morbidity, calculated by multiplying the incidences by their mean duration and cause disability weight |
| **incremental cost-effectiveness ratio** | Statistic used in cost-effectiveness analysis to summarize the cost-effectiveness of an intervention, calculated as the difference in cost between two possible interventions, divided by the difference in their effect. |
| **independent variable** | Variable whose variation does not depend on that of another variable. |
| **indirect (overhead) costs** | Costs that are not directly accountable to a cost object (for example, in research these may be costs for the institution). |
| **indirectly affected** | People who have suffered consequences other than, or in addition to, direct effects, over time. These may be due to disruption or changes in economy, critical infrastructure, basic services, commerce or work, and include social, health and psychological consequences. |
| **inductive research** | A ‘bottom-up’ approach to inquiry that involves building theories based on observation and analysis of data gathered in the field. |
| **infant mortality rate** | Rate of deaths of children under 1 year of age in a population, calculated as the number of these deaths multiplied by 1000, divided by the number of live births during the same period. |
| **influenza clade** | Group of virus strains that are believed to comprise of evolutionary descendants of a common virus ancestor. |
| **information bias** | Bias arising from measurement error. |
| **informed consent** | Process by which a person agrees to join a study having been informed about, and understood, its purpose. |
| **institutional review board (IRB)** | Administrative body that protects the rights and welfare of participants in research activities conducted under the auspices of the institution. |
| **Instrumental Activities for Daily Living (IADL)** | Activities that allow a person to live independently in a community. |

| Term | Definition |
|---|---|
| **instrumental variable** | A third variable used in regression analysis when the dependent and independent variables are influenced by each other. |
| **intercept dummy** | A binary variable that can take values of either 0 or 1 to split the sample into two distinct groups for the absence (=0) or presence (=1) of a dichotomous characteristic (such as Female/Male), allowing the fitted value of the dependent variable to differ by a constant amount. |
| **interconnectivity** | An attribute of complex adaptive systems where the component parts are loosely or tightly coupled with one another, adding to the complexity of the system. |
| **internal validity** | Extent to which an individual study can answer the research question. |
| **Internally Displaced Person (IDP)** | Persons or groups of persons who have been forced or obliged to flee or to leave their homes or places of habitual residence, in particular as a result of, or in order to, avoid the effects of armed conflicts, situations of generalized violence, violations of human rights or natural or human-made disasters, and who have not crossed an internationally recognized State border. |
| **International Statistical Classification of Diseases and Related Health Problems (ICD)** | Globally used tool to categorize diseases. |
| **Internet of Things (IoT)** | System of interrelated computing devices, mechanical and digital machines provided with unique identifiers (UIDs) and the ability to transfer data over a network without requiring human-to-human or human-to-computer interaction. |
| **interpretivist paradigm** | A worldview that sees knowledge, meaning and truth as subjective and multiple. It is a qualitative research paradigm applied to the exploration of social phenomenon and human experience. |
| **interquartile range** | Measure of statistical dispersion, being equal to the difference between 75th and 25th percentiles. |
| **interrupted time series** | Research design that collects observations at multiple time points before and after an intervention or exposure, which attempts to detect whether it has had an effect significantly greater than the underlying trend. |
| **intersectionality** | Interconnected nature of social categorizations (such as race, class, and gender) as they apply to a person or population. |
| **interval data** | Data measured on a scale in which the points are equal distances apart. |

| Term | Definition |
|---|---|
| **intra-cluster correlation coefficient** | Measure of the relatedness, or similarity, of clustered data. |
| **intrinsic** | An "intrinsic case study" is an approach to case study research in which the researcher intends to look at the case itself because the subject is unusual or unique. |
| **iterative logic model** | Logic models that are adapted at any point in the research or evaluation study to reflect findings or new knowledge. |
| **Japan Disaster Rehabilitation Assistance Team (JRAT)** | Team to assist, in particular, older people and people with disability from the very early phase of evacuation. |
| **judgemental sampling** | Sampling based on the opinion of an expert. |
| **kernel matching** | A non-parametric matching estimator that uses weighted averages of all units in the comparison group to identify the closest match to each treated unit creating the nearest comparison in terms of propensity score. |
| **key informant interview** | Qualitative in-depth interviews with people with relevant knowledge or expertise. |
| **life-years gained** | Additional number of years of life that a person lives as a result of receiving a treatment. |
| **Light Detection and Ranging (LiDAR)** | Method for measuring distances by illuminating the target with laser light and measuring the reflection with a sensor. |
| **Likert scale** | Rating scale used to measure attitudes or opinions on a linear scale with respondents asked to choose one from a number of values. |
| **line list** | Table that summarizes information about persons who may be associated with a disease outbreak. |
| **local area treatment effect (LATE)** | Average effect of an intervention among a specific subset of people. |
| **Local Tree Shape** | Genealogical tree-based model, estimated recent clade growth from information stored in the local shape of a haemagglutinin genealogical tree. |
| **logframe (logical framework)** | Array of different approaches to mapping a process. |
| **logic model** | Hypothesized description of the chain of causes and effects. |
| **logical framework (logframe)** | Array of different approaches to mapping a process. |
| **logistic (logit) regression** | Statistical model that uses a logistic function to model a binary dependent variable. |

| Term | Definition |
|---|---|
| **logit (logistic) regression** | Statistical model that uses a logistic function to model a binary dependent variable. |
| **longitudinal study** | Study that follows participants over time. |
| **machine learning algorithm** | The act of building a mathematical model based on sample data in order to make predictions or decisions without being explicitly programmed to do so. This can also be described as predictive analytics. |
| **machine science** | The use of advanced computational techniques to generate data analytics, hypotheses and develop models. |
| **machine-readable format** | Structured data in a format that can be processed by a computer. |
| **macroeconomic impacts** | Impact on the economy as a whole. |
| **market resources** | Commodities that are traded for money and have a defined price. |
| **masking** | Process of keeping a person's study-group assignment hidden after allocation to minimize bias. |
| **mean** | Most common measure of central tendency, calculated by the dividing the sum total of all observations by the number of records. |
| **measure of net benefit** | Benefits minus costs. |
| **median** | Middle value in a distribution of values. |
| **member-checking** | Technique used in qualitative research in which the participants check the findings. |
| **MeSH** | Controlled vocabulary for the purpose of indexing journal articles and books in the life sciences. |
| **meta-analysis** | Statistical combination of data from a series of studies (usually in a systematic review) to obtain a summary effect estimate. |
| **methodological search filters** | Search strategies designed to help people search the literature for studies of a particular design. |
| **middle-range theory** | Theory connecting high-level sociological theories with empirical knowledge. |
| **mid-interval population** | Estimate of the size of a population, calculated by adding together the number of people in the population at the start of the period of observation and the number at the end, and dividing this by 2. |
| **minimization** | Technique used to allocate participants to their intervention group in a randomized trial which seeks to balance participant characteristics across groups. |

| Term | Definition |
|---|---|
| **mixed method matrix** | A technique using a table to summarize and display the qualitative and quantitative data for a given case for integration during analysis; it enables researchers to view more information about the case during analysis. |
| **mixed methods research** | Research that uses both qualitative and quantitative methods. |
| **mode** | Observation or value that appears most frequently in a set of data. |
| **Multi-Cluster/Sector Initial Rapid Assessment (MIRA)** | Process designed to identify strategic humanitarian priorities during the first weeks following an emergency. |
| **multi-criteria decision analysis (MCDA)** | Analysis that combines findings from economic studies with additional decision-making factors. |
| **munted** | Before the 2010-2011 earthquakes in Canterbury, New Zealand, munted referred to an intoxicated person or something that was broken, but the word came to symbolize the way in which individuals interpreted and expressed their experiences of the post-disaster city. |
| **mutation** | Change in the genetic sequence (DNA/RNA). |
| **narrative exposure therapy** | Short-term psychological treatment strategy focusing on the management of trauma-spectrum disorders, such as post-traumatic stress disorder (PTSD) using a narrative approach. |
| **narrative research** | A type of qualitative research methodology that explores people's experiences as told in the form of stories from one or more individuals of interest. |
| **narrative systematic review** | Systematic review in which each included study is discussed, but without a synthesis of their overall results. |
| **National Disaster Inventory (or Registry)** | National system for understanding disaster risk that would act as the central repository of all publicly available risk information. |
| **natural hazard** | Hazards that are predominantly associated with natural processes and phenomena. |
| **natural language processing** | Subfield of linguistics, computer science, information engineering and artificial intelligence concerned with the interactions between computers and human languages. |
| **nearest neighbour matching** | Matching that pairs a given point with another, closest point. |
| **nearest-neighbour algorithm** | Non-parametric method used for classification and regression. |

| Term | Definition |
|---|---|
| **Nelder-Mead simplex method** | Statistical technique used to find the minimum or maximum of an objective function in a multidimensional space. |
| **net benefit** | Measure of the benefits minus the costs (including negative consequences) of an action or event. |
| **Neyman–Rubin potential outcomes model** | Statistical analysis of cause and effect based on the framework of potential outcomes. |
| **non-interference assumption** | The independence of the effects of an exposure or intervention across participants in an experiment setting. The non-interference assumption is met when the outcome of one participant only depends on whether they received the exposure or intervention or not, and not on the assignment to the exposure or intervention or factors related to other participants in the study. |
| **non-linearity** | An attribute of complex adaptive systems where the interconnected components of systems have asymmetrical relationships; when a fluctuation happens in one component of the system, it results in unpredictable fluctuations in other parts of the system which are connected. |
| **non-market resources** | Commodities that are not traded for money and do not have a defined price. |
| **non-probability sampling** | Use of a subset of the population to represent the whole population. |
| **non-response bias** | Bias when respondents differ from non-respondents. |
| **observational study** | Study to measure the effect of an intervention or exposure by observing the participants in their natural setting. |
| **odds ratio** | Ratio of the odds that an event occurred in one group (usually the intervention or exposure group) to the odds of the event occurring in a second group (usually the control group). |
| **open coding** | An analysis process in Straussian Grounded Theory in which the researcher labels and categorizes information in the data, before attempting to relate categories to each other via axial coding. |
| **open data** | Data that anyone can access, use and share. |
| **open-sourcing** | The development of data or materials that will become freely available, where there is often no clear ‘call’ to work (for example, open sourced software programmes). |
| **ordinal data** | Categorical data where the variables have natural, ordered categories. |

| Term | Definition |
|---|---|
| **ordinary least squares (OLS) approach** | Statistical method for estimating the unknown parameters in a linear regression model. |
| **outcome** | The disease, condition or other endpoint being measured. |
| **outsourcing** | The act of a company hiring a party outside the company in order to perform services and create goods. |
| **overhead (indirect) costs** | Costs that are not directly accountable to a cost object (in research these may be costs for the institution, for example). |
| **paradigm** | Set of beliefs or worldviews. |
| **participant narrative** | Data generated by talking directly to participants through interviews and focus groups. |
| **participant observer** | A method of data collection in which the researcher becomes immersed in the day-to-day lives of the group they are researching, both observing and participating in the world around them. |
| **participation equation** | A probit or logit regression in which the dependent variable is dichotomous, taking the value of 1 for those who took part in the intervention and 0 for those who did not. |
| **participatory action research** | An action-oriented approach to inquiry that is a collaboration between researchers and participants to challenge inequality and bring about social change. |
| **payer perspective** | Focus on the health and non-health economic outcomes borne by the payer of health care. |
| **peer production** | Development of data or materials that will become freely available, where there is often no clear ‘call’ to work (for example, through the collaboration of many). |
| **peer review** | Evaluation by others working in the same field. |
| **period prevalence** | Existing and new cases that happen over a set period of time. |
| **periodic function** | Mathematical function that repeats its values in regular intervals or periods. |
| **phenomenology** | A qualitative research methodology that seeks to understand the universal ‘essence’ of the experience of a phenomenon. This approach goes beyond the individual experience to describe the common meaning for several individuals. |
| **phenotypic property** | Observable characteristics of an organism. |

| Term | Definition |
|---|---|
| **pilot study** | Small, preliminary study usually done before a definitive study. |
| **placebo** | A substance that has no therapeutic effect and is used as a control in some experimental research to minimize bias. |
| **placebo effect** | Effect produced by a placebo or intervention which cannot be attributed to the properties of the placebo or intervention itself and is due to the person's belief in the effects of the intervention. |
| **point prevalence** | Existing case at a particular point in time. |
| **polytomous** | Data that can take one of more than two values. |
| **population** | Group of people being studied. |
| **positivist paradigm** | A worldview that sees truth as objective and seeks to explain and predict knowledge using the scientific method. |
| **postpositivism** | A worldview based on the assumption that findings cannot be proven beyond doubt, but that confidence is improved through robust measures of reliability and validity. |
| **pragmatic paradigm** | A common epistemological worldview for mixed method research which focuses on the research problem and selecting the best method to address the problem, which may draw on qualitative or quantitative methods. |
| **pragmatic trial** | Study to determine the effects of an intervention when used in routine practice. |
| **Precaution Adoption Process Model (PAPM)** | Model to explain how a person makes decisions to take action and how they translate that decision into action. |
| **PRECEDE-PROCEED model** | Structure used to assess health needs for designing, implementing, and evaluating health promotion and other public health programmes. |
| **prevalence** | The number of cases in a defined population at a specific point in time. |
| **prevalence-based YLD** | Population metric of life years lost due to morbidity, calculated by multiplying the number of prevalent cases during a given period by their cause disability weight. |
| **primary data** | Data collected by a researcher from first-hand sources (for example through surveys, interviews or experiments). |
| **primary prevention** | Strategies to prevent a disease from occurring. |

| Term | Definition |
|---|---|
| **principal component** | Linear combinations of the original variables, which can be used as surrogates for the original variables. |
| **principal components analysis (PCA)** | Transforming the high-dimensional data into a lower-dimensional form, without losing too much information. |
| **principal investigator** | Lead person for a research project. |
| **PRISMA** | Reporting guideline for systematic reviews and meta-analyses. |
| **probability sampling** | Sampling based on some form of random sampling. |
| **probit regression** | Statistical technique where the dependent variable can take only two values. |
| **process-based logic model** | Hypothesized description that focuses on theorizing aspects of complexity between the processes occurring as part of an intervention and its multiple outcomes. |
| **programme theory** | Hypothesis explaining how an intervention is expected to lead to a change in the outcome. |
| **PROGRESS PLUS** | Acronym used to identify characteristics that stratify health opportunities and outcomes. PROGRESS stands for: Place of residence; Race/ethnicity/culture/language; Occupation; Gender/sex; Religion; Education; Socioeconomic status; Social capital. PLUS refers to: Personal characteristics associated with discrimination; Features of relationships; Time-dependent relationships. |
| **proofs** | Document showing what an article will look like when it is published. |
| **propensity score matching** | Statistical matching technique that estimates the effect of an intervention or exposure by accounting for covariates that predict that someone will receive it. |
| **prospective study** | Study that follows participants over time into future. |
| **proximity searching** | A technique that searches for terms that appear close together in the text, but not necessarily directly next to each other. For example, primary care might also be referred to as primary health care, so by using one of the operators available within the databases, it is possible to search for one concept that might be expressed in several different ways. Each database uses a different set of operators, so it is necessary to refer to the online help for guidance on the use of proximity operators. |
| **proxy consent** | Process by which people give consent on behalf of someone else. |
| **proxy measure** | Variable that is easy to measure and can act as a substitute for the variable that is of particular interest. |

| Term | Definition |
|---|---|
| **public health emergency preparedness (PHEP)** | Health department readiness to respond to different types of public health threats (such as infectious diseases, nuclear events, chemical spill or radiation, natural disasters). |
| **publication bias** | Bias in which the publication of a study is influenced by its results. |
| **purposive sampling** | Technique used to select certain members of a population to participate in a study. |
| **qualitative research** | Scientific method of observation to gather non-numerical data (for example, to assess perceptions and beliefs). |
| **Quality-Adjusted Life-Year (QALY)** | Measure of additional life expectancy combined with the health-related quality of life. |
| **quantitative research** | Scientific method of observation to gather numerical data. |
| **quasi-experimental design** | Study used to estimate the causal impact of an intervention on target population without random assignment. |
| **random-digit dialling** | Technique used to select people for involvement in a telephone survey by generating telephone numbers at random. |
| **randomized trial** | Study in which patients are allocated randomly to one of the groups being compared. |
| **range** | Distance between the highest and the lowest values in a distribution. |
| **rapid needs assessment** | Process conducted immediately after the onset of a disaster to assess the disaster-affected areas and needs of disaster victims. |
| **raster** | Grid of cells and pixels which can be stored as images. |
| **ratio data** | Form of continuous data, which have the same properties as interval data and an absolute zero point. |
| **Read codes** | Clinical terminology system that was widely used in general practice in the United Kingdom. |
| **realist ethnography** | A traditional approach to ethnography (the study of social behaviours of a culture-sharing group) in which the researcher objectively observes and reports the information learned. |
| **realist evaluation** | A theory-driven evaluation method which emphasizes the interaction of the context and mechanism to produce an outcome. |

| Term | Definition |
|---|---|
| **Reasoned Action Approach (RAA)** | Framework for predicting human social behaviour based on how attitudes towards the behaviour, perceived norms, and perceived behavioural control determine people's intentions, while people's intentions predict their behaviours. |
| **record review** | Technique used to obtain retrospective data from a series of records. |
| **reflexivity** | A continuous process undertaken by qualitative researchers that involves contemplating how their choices, feelings, assumptions, and experiences contribute to the creation of knowledge in research. |
| **refugee** | A person who cannot return to their country of origin owing to a well-founded fear of persecution or serious and indiscriminate threats to life, physical integrity or freedom. |
| **region of common support** | The area of overlap in the range of propensity scores between treatment and comparison groups. Impact estimates are best calculated after discarding observations which fall outside the range of common support. |
| **regression analysis** | Statistical technique to estimate the relationships between a dependent variable and one or more independent variables. |
| **regression discontinuity design** | Evaluation design in which the intervention or exposure and comparison groups are identified as being those just either side of some threshold value of a variable. This variable may be a score or observed characteristic (for example, age or land holding) used in determining the eligible population for the study, or it may be a variable found to distinguish participants from non-participants through data analysis. |
| **relative risk / risk ratio** | The ratio of the incidence of a disease among exposed people to the incidence of the disease among unexposed people. |
| **reporting guideline** | Document providing guidance on how to report a particular type of study. |
| **REporting of studies Conducted using Observational Routinely collected health Data (RECORD) statement** | Reporting guideline for studies that use routinely collected health data. |
| **REPRISE** | Reporting guideline for priority setting of health research. |
| **research ethics committee** | An independent group that oversees the ethical aspects of a research study. |

| Term | Definition |
|---|---|
| **research paradigm** | System of beliefs and practices that influence how researchers select both the questions they study and the methods they use to study them. |
| **research protocol** | Document describing the background, rationale, objectives, design, methodology, statistical considerations, and organization of a research study. |
| **resilience** | The ability of a system, community or society exposed to hazards to resist, absorb, accommodate, adapt to, transform and recover from the effects of a hazard in a timely and efficient manner, including through the preservation and restoration of its essential basic structures and functions through risk management. |
| **retrospective study** | A type of study design that identifies an outcome and examines information that already occurred, it does not follow study participants into the future. Also known as a "historic cohort". |
| **return on investment analysis** | Analysis that calculates the size of the difference between positive consequences and costs, calculated by subtracting costs from benefits and expressing this figure as a proportion of overall costs. |
| **ring vaccination** | Strategy to inhibit the spread of an infectious disease by vaccinating only those who are most likely to be infected because they are (or have been) in close contact with an infected individual. |
| **risk factor** | Any attribute, characteristic or exposure of an individual that increases the likelihood of developing a disease or injury. |
| **salutogenesis** | Medical approach focusing on factors that support human health and well-being, rather than on risk factors for disease. |
| **sample size** | Number of participants in the study. The intended sample size is the number of participants planned to be included in the study, which is usually determined through a statistical calculation before the study begins. |
| **sampling frame** | List of people forming a population from which a sample is taken. |
| **scoping review** | Research synthesis that maps the existing literature on a particular topic or research area. |
| **secondary data** | Data collected by someone other than the user. |
| **secondary prevention** | Strategies to prevent a disease from worsening or recurring. |
| **seed money** | Funding allocated to start a project. |

| Term | Definition |
|---|---|
| **selection bias** | Bias in choosing the individuals or groups to take part in a study, which might make them systematically different from those who do not take part. |
| **selective coding** | The analytical process in Straussian grounded theory in which the researcher selects the central concept in the data to be the core category (theory) to which all other categories relate. |
| **selective reporting bias** | Bias in which the publication of part of a study is influenced by the associated results. |
| **self-efficacy** | A person's belief in their capacity to do a given task or achieve a specific level of performance. Self-efficacy consists of both confidence and perceived control; it is linked to motivation and behavioural perseverance in the face of obstacles. |
| **self-empowerment approach** | A self-empowerment approach focuses on empowering an individual to make positive choices and exercise control over their physical, social and external environments. |
| **self-organization** | An emergent property of complex adaptive systems where actors within the system make adjustments to adapt to changing context; in social systems it is often behavioural adjustments made by people within a system. |
| **semi-structured interview** | A method of research in which the interviewer uses a framework but allows new topics to be discussed depending on what is said by the interviewee. |
| **Sendai Framework for Disaster Risk Reduction 2015-2030** | Voluntary, non-binding agreement covering the period 2015-2030 which recognizes that the State has the primary role of reducing disaster risk but that responsibility should be shared with other stakeholders, including local government, the private sector and other stakeholders. It aims for the substantial reduction of disaster risk and losses in lives, livelihoods and health and in the economic, physical, social, cultural and environmental assets of persons, businesses, communities and countries. |
| **Sendai Framework Monitor (SFM)** | Management tool to help countries to develop disaster risk reduction strategies, make risk-informed policy decisions and allocate resources to prevent new disaster risks. |
| **sensitive search** | In searching, a sensitive search is one with high recall and low precision. This means that more of the relevant articles are retrieved but at the expense of picking up more unwanted articles. |

| Term | Definition |
|---|---|
| **sensitivity analysis** | Analysis that determines how the results are affected by decisions made in conducting the analysis. |
| **setting approach** | An approach that considers the interaction of multiple components which form an entire system. Interventions integrating these components are established to reduce the risk factors contributing to diseases |
| **shelter in place** | Remain or take immediate refuge in a protected location relevant to the risk. |
| **simple random sampling** | Sampling technique that selects people from a sample at random. |
| **simple randomization** | Technique used to allocate participants to their intervention group in a randomized trial which uses a chance process with no attempt to balance the characteristics of the groups. |
| **simulation optimization (SIMOP)** | Process of finding the best input variable values from among all possibilities without explicitly evaluating each possibility. |
| **SNOMED-CT** | Collection of medical terms providing codes, terms, synonyms and definitions used in clinical documentation and reporting. |
| **snowball sampling** | Technique in which study participants suggest additional participants from among others that they know. |
| **social cognitive theory** | An interpersonal theory, which proposes that learning happens in a context that is dynamic and with reciprocal interaction of the person, environment and behaviour. |
| **social constructionism** | A worldview in qualitative research that recognizes that public knowledge and meaning are constructed and sustained through social interaction. It acknowledges that multiple realities co-exist (that is, there is no one universal truth). |
| **social constructivism** | A worldview in qualitative research with many similarities to social constructionism, but distinguished from it by its focus on how individuals learn through social interaction within their peer group. |
| **social determinants of health** | Economic and social conditions that influence individual and group differences in health status. |
| **social media** | Websites and other applications that enable users to create and share content or to participate in social networking online. |
| **social network analysis** | Process for investigating social structures through the use of networks and graph theory. |

| Term | Definition |
|---|---|
| **social norms** | Collective representations of acceptable group conduct as well as individual perceptions of particular group conduct. |
| **societal perspective** | Focus on the health and non-health economic outcomes borne by a society. |
| **socio-ecological approach** | Technique used to understand the interrelations among various personal and environmental factors. |
| **somatic symptom** | Health-related symptoms that cause significant distress or disruption in daily living. |
| **Source-Pathway-Receptor approach** | Technique used to describe the flow of a contaminant from a source, through a conducting pathway to a receptor. |
| **specific search** | In searching, a specific search is one with lower recall and higher precision. This means that more of the articles retrieved will be relevant, but there is a risk of missing some significant papers. |
| **SPICE Framework** | Framework for specifying research questions, which includes Setting, Perspective, Intervention, Comparison and Evaluation. |
| **staged logic model** | Logic model that is adapted or changed on the basis of interim findings or new knowledge, at planned stages of the study. |
| **Staging Care Unit (SCU)** | Unit used to select patients who will be transported to areas that have not been affected by a disaster. |
| **standard deviation** | A measure of how spread out numbers are, calculated by squaring and summing the difference between each observation and the arithmetic mean. |
| **standard error** | Measures the amount of variance in a sample mean, calculated by dividing the standard deviation by the square root of the number of observations in the sample. |
| **standard operating procedure** | Document describing how to perform a procedure. |
| **static logic model** | Logic model that is specified before the research or evaluation study, and remains in place without iteration throughout the study. |
| **stepped-wedge cluster randomized trial** | Design in which observations are collected from cluster during a baseline period in which no clusters are exposed to the intervention, followed by, at regular intervals (steps) when a cluster (or group of clusters) is randomized to receive the intervention and all participants are measured again. |

| Term | Definition |
|---|---|
| **stochastic modelling** | Tool for estimating probability distributions of potential outcomes by allowing for random variation in one or more inputs over time. |
| **Straussian grounded theory** | A structured approach to grounded theory (qualitative research methodology that generates theory grounded in data) that uses open coding, axial coding, and selective coding as steps in data analysis. |
| **strengths-based approach** | A collaborative approach that identifies and builds on existing capabilities of individuals, groups, organizations, or systems within the community to address a problem (see also asset-based approach). |
| **STROBE** | Guideline for strengthening the reporting of observational studies in epidemiology. |
| **structural analysis** | An analytic strategy in narrative research that focuses on exploring how a story was told (that is to say structured) by the research participant. |
| **Structured Interview Matrix** | Technique used for conducting large focus groups and promoting consultation with a variety of stakeholders. |
| **subject headings** | Controlled vocabulary for the purpose of indexing journal articles and books in the life sciences. |
| **summative evaluation** | Evaluations conducted after the conclusion of a programme, or examining the impact of the programme. |
| **Surveillance in Post Extreme Emergency and Disaster (SPEED)** | Surveillance system developed by WHO and the Ministry of Health of the Philippines to collect data following a disaster. |
| **susceptible-infected-removed (SIR) model** | Mathematical model that can be used to predict the number of people infected by an infectious disease in a population over time. |
| **syndromic surveillance** | A method of surveillance that uses health-related data based on clinical observations rather than laboratory confirmation of diagnoses. |
| **systematic review** | Method for knowledge synthesis that collects and critically analyses multiple research studies on a specific topic. |
| **systematic sampling** | Sampling of people from an ordered sampling frame. |
| **systems lens** | Similar to systems thinking, a way of looking at a problem or situation in terms of the relationships between interconnected components of a complex system. |

| Term | Definition |
|---|---|
| **systems thinking** | An approach to research which views the dynamic and complex context surrounding a problem, including multi-level influences on different interrelated components. |
| **systems-based logic models** | Logic model that aims to theorize aspects of complexity around the relationship between an intervention and the broader context and how these interact. |
| **targeted sampling** | Technique used to recruit adequate numbers of people from within a specific population. |
| **tertiary prevention** | Strategies to reduce the complications of a disease. |
| **thematic analysis** | Technique used to identify, analyse and interpret patterns of meaning in qualitative data. |
| **theory of change** | Model used to illustrate how and why a desired change is expected to occur, and how they affect the outcome in a particular context, often used in complex interventions. |
| **Theory of Planned Behaviour (TPB)** | Theory linking a person's beliefs and behaviour, stating that intention toward attitude, person's norms and perceived behavioural control shape their behavioural intentions and behaviours. |
| **Theory of Reasoned Action (TRA)** | Theory to explain the relationship between attitudes and behaviours, which is used to predict how individuals will behave based on their pre-existing attitudes and behavioural intentions. |
| **time series analysis** | Statistical technique for analysing data that is spaced out over time. |
| **time series design** | Experimental design that observes people or populations over a defined time period. |
| **time stratified model** | Statistical model that splits data into different time intervals. |
| **time variance** | Variance in the value of an estimate over time, as a result of one or more factors (including discount rates and inflation). |
| **Tobler's First Law of Geography** | "Everything is related to everything else. But near things are more related than distant things" |
| **Transtheoretical Model (The Stages of Change Model)** | Model of behaviour change that assesses a person's readiness to act on a new healthier behaviour, and provides strategies, or processes of change to guide the person. |
| **triangulation** | Using different methods to provide a more complete answer for a research question. |

| Term | Definition |
|---|---|
| **triple billion goals** | WHO goals to ensure 1 billion more people benefit from universal health coverage, 1 billion more people are protected from health emergencies and 1 billion people improve their overall health over 5 years. |
| **t-test** | Statistical test used to determine if there is a significant difference between the means of two groups. |
| **type 1 error** | Rejection of a true null hypothesis, which is also known as a "false positive" finding. |
| **type 2 error** | Non-rejection of a false null hypothesis, which is also known as a false negative. |
| **uncertainty principle** | Approach used to include people in research where they and others making a decision about their inclusion have sufficient uncertainty about their likely outcomes to justify including them in the study. |
| **univariate analysis** | Statistical analysis that uses only one variable. |
| **universal health coverage (UHC)** | Process by which all people and communities can use the promotive, preventive, curative, rehabilitative and palliative health services they need, of sufficient quality to be effective, while also ensuring that the use of these services does not expose the user to financial hardship. |
| **validation** | Confirmation of the accuracy of a measure or design. |
| **Vancouver style** | Citation style used in documents, in which numbers are embedded in the text and the citations are listed in numerical order. |
| **vector** | 1. An insect or other animal that normally transports an infectious agent that constitutes a public health risk;<br>2. An insect or any living carrier that transports an infectious agent from an infected individual to a susceptible individual or its food or immediate surroundings. |
| **venue-based time-location sampling** | Technique used to recruit people based on where or when they gather. |
| **vicious cycle** | Sequence of reciprocal cause and effect leading to a worsening of the situation. |
| **virtuous circle** | Sequence of reciprocal cause and effect leading to an improvement in the situation. |
| **visualization** | Spatial analysis method, resulting in maps that describe spatial patterns. |
| **vulnerability** | The conditions determined by physical, social, economic and environmental factors or processes which increase the susceptibility of an individual, a community, assets or systems to the impacts of hazards. |

| Term | Definition |
|---|---|
| **vulnerable groups** | Individuals who share one or several characteristics that are the basis of discrimination or adverse social, economic, cultural, political or health circumstances and that cause them to lack the means to achieve their rights or otherwise enjoy equal opportunities. |
| **Web 2.0 technologies** | A website or application that enables enhanced user engagement through creation or sharing of online user-developed content, and allows users to create, share, collaborate, and communicate. |
| **Wisdom of the crowd** | A theory that says a group of people will provide a better answer than any individual. This type of crowdsourcing uses a crowd to conduct activities that require intelligence |

# Introduction

# 1.0

# 1.1

# Introduction

## Authors

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### 1.1.1 The rationale for this Guidance

As the world and its population face ever-increasing challenges from emergencies and disasters of all kinds, the policy-makers, practitioners and community actors involved in health emergency and disaster risk management (Health EDRM) need to be able to access, understand and use the relevant evidence in order to be able to make decisions, develop strategies, and take actions that are well informed, effective and efficient in reducing health risks and consequences, thus alleviating suffering, saving lives and reducing the associated social, economic, environmental and cultural impacts. This evidence needs to come from reliable research, which has been robustly designed, well conducted and properly reported. This evidence will inevitably also highlight the need for new research to resolve ongoing uncertainties and fill knowledge gaps, and so Health EDRM decision makers and practitioners will also need to become involved in the generation of research and build effective collaborations with the research community.

Developed following extensive peer-review by multi-national, multi-disciplinary teams of people, the aim of this book is to:

- improve the quality of research in Health EDRM
- improve the quality of the policy, practice and guidance that is supported by evidence from this research
- increase research capacity among researchers and the research community, including new researchers, experienced researchers and teachers of research, and

- strengthen the collaboration and engagement between the research community and policy-makers, practitioners and stakeholders for improved Health EDRM.

The unique collection of chapters contained in this book provide straightforward, practical guidance on how to plan, do and report a wide variety of studies that can answer quantitative and qualitative questions in different settings, with specific emphasis on health-related disasters. Case studies of direct relevance to Health EDRM provide real-life examples of research, to illustrate the methods and their impact.

### 1.1.2 The context to this Guidance

The main driver for this book – which arose from the work of the WHO Thematic Platform for Health Emergency and Disaster Risk Management Research Network (Health EDRM RN) – is the shared aim of Health EDRM stakeholders to reduce the risks and consequences for the many millions of people worldwide whose health is affected by emergencies and disasters each year.

The context to the book emanates from the WHO Health EDRM Framework and the identified need to strengthen research and the research community, as described in the aspirations of the Health EDRM RN (see Chapter 1.2): The Health EDRM RN recognized the need to promote high quality research methods to those who commission and conduct research on Health EDRM, as well as the wide range of decision makers practitioners and community actors who need to use this research to inform evidence-based policies, programs and practice. It reflects the need for evidence-based policy and practice to implement the Health EDRM Framework, Sendai Framework on Disaster Risk Reduction 2015–2030, the International Health Regulations (2005), the United Nations (UN) Sustainable Development Goals (SDGs) and other relevant global, regional and national frameworks in health and other sectors.

The book provides guidance across a wide range of research, taking a systematic approach to discuss the type of research that is needed to generate relevant evidence for managing risks and consequences of emergencies and disasters. This research includes observational and experimental studies, and those that use qualitative or quantitative data, or both. When using the book, readers are encouraged to take account of the specific setting of the health risks of any emergency or disaster, including national capacities and the impacts that are directly and indirectly health-related.

The chapters have been written by a wide range of more than 100 international authors with practical experience and expertise in a wide range of areas – including research, practice and policy making – and peer reviewed by experts with a similar breadth and depth of knowledge. Each chapter provides signposting to further reading or sources of information that go beyond the issues that can be covered in a single chapter.

### 1.1.3 What you will find in this book

The chapters of the book are organized into six sections:

1. Introduction
2. Identifying and understanding the problem
3. Determining the scope of your study
4. Study design
5. Special topics to demonstrate research processes and benefits
6. How to become a researcher.

The book begins with an overview of the Health EDRM framework and the role of research (Chapter 1.2) to explain the context, followed by a historical review of the impact of emergencies and disasters on public health and the development of Health EDRM policies, focusing on Japan as a case study (Chapter 1.3).

Sections 2, 3 and 4 cover three major aspects of the research process: (i) identifying and understanding the problem that needs to be studied; (ii) determining the research question and developing a scoping study; and (iii) designing and conducting the main study.

The book concludes with a section on the practicalities of becoming a researcher and a glossary to explain terms that might be unfamiliar to some readers.

The first step in identifying and understanding the Health EDRM problem that needs to be studied is to investigate the underlying epidemiology: Chapter 2.1 describes some common impacts of emergencies and disasters on deaths, injuries and other health problems. This is discussed in more detail in Chapter 2.2, in relation to measuring the health impacts of emergencies and disasters. Chapter 2.3 discusses the assessment of burden of disease in general, while Chapter 2.4 describes various databases and registers relevant to the study of disaster epidemiology. The challenge of identifying and obtaining data from high risk groups is discussed in Chapter 2.5, and Section 2 ends with a discussion of the use of systematic reviews to identify, appraise and synthesize existing, relevant research studies (Chapter 2.6).

Once we have a good understanding of the problem that needs to be studied, Section 3 leads us on to the planning of research process. This might include asset mapping to show what resources are available for the research or to help measure its impact (Chapter 3.1), identifying risk factors (Chapter 3.2) and designing an intervention to test (Chapter 3.3). It is also important to consider the ethical implications of conducting research (Chapter 3.4). Researchers then need to finalize their research question (Chapter 3.5) and, if necessary, conduct a scoping review (Chapter 3.6), drawing on the information available in existing collections of research relevant to disasters (Chapter 3.7).

When the research question is clear, the appropriate study design must be chosen to answer it. Chapter 4.1 discusses the importance of this, outlining some of the study designs that are available, with a particular focus on using randomized trials to assess the comparative effects of different interventions, actions and strategies. Chapter 4.2 provides an introduction to the statistics that are likely to be used in many of the studies. Some of the more challenging issues related to study design and statistics that might be used when individual randomization is not possible are tackled in Chapter 4.3 (cluster randomized trials), Chapter 4.4 (collection and management of high quality data) and Chapter 4.5 (advanced statistical methods). The use of modelling techniques is discussed further in Chapters 4.6 and 4.7, with the focus of Chapter 4.7 being economic evaluations. Chapter 4.8 introduces the potential for geographic information systems to help with disaster health research and Chapter 4.9 does similar for real-time syndromic surveillance systems. Part of the planning for any research may include a need to understand the pathway from actions to outcomes (Chapter 4.10) and to plan for the communication and implementation of the findings of the research (Chapter 4.11). In some circumstances, the most appropriate type of research will be a qualitative study or one that employs both qualitative and quantitative methods in a mixed methods design; these are discussed in Chapters 4.12 and 4.13 respectively. Chapter 4.14 shows the potential advantages of taking the opportunities presented by natural variations, by using a natural experiment design. Section 4 concludes with a chapter on monitoring and evaluation studies (Chapter 4.15).

The special topics presented in Section 5 include disaster mental health research (chapter 5.1), the use of crowdsourcing to gather data (Chapter 5.2), and research with refugees and internally displaced populations (Chapter 5.3) or indigenous people (Chapter 5.4).

Section 6 is dedicated to some of the important practical aspects of conducting research relevant to Health EDRM, beginning with some of the steps that will help someone become a successful researcher (Chapter 6.1). Chapter 6.2 covers the identification of existing literature that might help in becoming a researcher or designing a new study. Chapters 6.3 and 6.4 outline key things to consider when preparing an application for funding and obtaining ethical approval for a study, while Chapter 6.5 highlights specific issues encountered in relation to doing research in the field. Chapter 6.6 provides guidance on writing up and publishing the report of the study. Finally, Chapter 6.7 concludes the book with some more examples of the types of research that have been done in Health EDRM.

### 1.1.4 Key messages

Evidence is vital to well-informed decision making in Health EDRM. The research that provides this evidence must be high quality and fit for purpose. This book aims to provide guidance for researchers, would-be researchers, policy-makers and practitioners in order to:

- improve the quality of research in Health EDRM
- improve the quality of the policy, practice and guidance that is supported by evidence from such research
- increase research capacity among researchers and the research community, including new researchers, experienced researchers and teachers of research, and
- strengthen collaboration and engagement between the research community and policy-makers, practitioners and stakeholders for improved Health EDRM.

## 1.2

# Background: Health EDRM and research

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### 1.2.1 Introduction

Over recent decades, a number of risk drivers – including unplanned urbanization, unmitigated climate change, weak health systems and conflicts – have resulted in increased risks of emergencies and disasters *(1)*. The impacts of emergencies and disasters on human health have also become more severe, in part due to the role played by increasing exposure and vulnerability, such as poverty, people living in risk-prone areas, and changes in the social dynamics and age profiles of communities. The toll taken by emergencies and disasters on people's health is profound, often persisting well after the headlines fade. Between 2008 and 2017, disasters caused by natural hazards affected an average of nearly 200 million people a year, caused nearly 70 000 deaths annually and led to economic losses of more than US$160 billion annually *(2)*. Many tens of millions more are affected by conflict *(3)*. Some emergencies and disasters are large, and become national, regional or even global crises – these range from cyclones and drought, to conflicts and major disease outbreaks. However, more localized emergencies – such as traffic crashes, landslides and fires – can also be devastating in their collective costs to human lives, livelihood and health.

Too often, health emergencies and disasters set back a country's development, sometimes for decades, jeopardizing universal health coverage (UHC) along with the country's other development agendas. They shatter the aspirations of children and adults, destroying the communities they live in or call home. Health emergencies and disasters can overwhelm health systems and decimate the economies that fund them. The various actors in health and other sectors who are engaged in trying to prevent hazardous events and their health effects and then stopping them from becoming emergencies or disasters – by preparing for their occurrence, responding to and recovering from them, must be able to access and use research to inform their decision making, and where uncertainties remain, they must be able to resolve these uncertainties by facilitating new research.

In 2015, the Third UN World Conference on Disaster Risk Reduction established the Sendai Framework for Disaster Risk Reduction 2015-2030 (Sendai Framework), a global agreement that introduced a framework for action to enhance the resilience of communities, and of health and social systems. The Sendai Framework, which includes more than 30 references to health issues specifically, includes health in its goal of "the substantial reduction of disaster risk and losses in lives, livelihoods and health " *(4–5)*. It also emphasizes the importance of improving the scientific evidence base in order to advance health emergency and disaster risk management (Health EDRM). Reducing the health risks and consequences of emergencies and disasters is one of the most pressing priorities, and is central to achieving the "triple billion" goals of WHO's 13th General Programme of Work, in which WHO aims to ensure that by 2023, one billion more people benefit from UHC, one billion more people have better protection from health emergencies, and one billion more people enjoy better health and well-being *(6)*.

### 1.2.2 WHO Health EDRM Framework

The WHO Health EDRM Framework, published in August 2019, is a substantial response to this challenge of managing the health risks of emergencies and disasters across the world *(7)*. It emphasizes the critical importance of prevention, preparedness and readiness, together with response and recovery, to save lives and protect health. It also emphasizes the need to work together, because Health EDRM is never the work of one sector or agency alone. It shows how the entire health system and the whole-of-society can and must be fundamental in all these efforts. The Health EDRM Framework also details the clear need for communities to be in the driving seat. Although emergencies affect everyone, those whose situations and circumstances render them the most vulnerable are disproportionately affected (see Chapters 2.5 and 3.2). The needs and rights of the poorest, as well as of women, children, people with disabilities, older persons, migrants, refugees and displaced persons, and people with chronic diseases and other underlying health conditions, must therefore be at the centre of the efforts made.

Reducing the health risks and consequences of emergencies is vital to local, national and global health security and to building the resilience of communities, countries and health systems. Sound risk management is essential in order to safeguard the development and implementation of the SDGs, including the pathway to UHC, the Sendai Framework, the International Health Regulations (IHR) (2005), the Paris Agreement on Climate Change and other related global, regional and national frameworks.

The Health EDRM Framework does not replace these other frameworks, but rather serves as a bridge across them, striving for stronger coherence between them. The Health EDRM Framework builds on past achievements, good practices and the trends evident in health and multi-sectoral emergency and disaster risk management practices worldwide; it brings together local, national and international work on humanitarian action, epidemic preparedness and response, disaster management and health systems strengthening into a common and inclusive approach.

Many countries have strengthened their capacities to reduce the health risks and consequences of emergencies and disasters by implementing multi-hazard disaster risk management, the IHR (2005) and health systems strengthening. Nonetheless, many communities remain highly vulnerable to a wide range of hazards. Fragmented approaches to the management of risks associated with different types of hazards – including an over-emphasis on reacting to events, instead of preventing them and preparing properly in order to be ready for response – as well as gaps in coordination both within health systems, and between health and other sectors, have hindered the ability of communities and countries to achieve optimal development outcomes, including for public health. The Health EDRM Framework is intended to help resolve such issues by providing a common language and a comprehensive approach that can be adapted and applied by all the actors – in health and other sectors – working to reduce the health risks and consequences of emergencies and disasters.

The Health EDRM Framework also focuses on improving health outcomes and well-being for communities at risk in different contexts, including in fragile settings, and low- and high-resource settings. It places emphasis on assessment, communication and risk reduction across the continuum of prevention, preparedness, readiness, response and recovery. This will help build the resilience of communities, countries and health systems.

Health EDRM is derived from the disciplines of risk management, emergency management, epidemic preparedness and response, as well as health systems strengthening, and draws on the expertise and field experience of many of those who contributed to the development of the Framework. It is fully consistent with and helps to align policies and actions for health security, disaster risk reduction, humanitarian action, climate change and sustainable development. Effective implementation of Health EDRM is therefore critical to achieving UHC in all country contexts.

Health EDRM aims to transform the policy, practice and culture with respect to the management of emergencies and disasters; the change in approach it brings is summarized in Table 1.2.1.

Table 1.2.1 Summary of change in approach through Health EDRM *(7)*

| From | | To |
|---|---|---|
| Event-based | → | **Risk-based** |
| Reactive | → | **Proactive** |
| Single-hazard | → | **All-hazard** |
| Hazard-focus | → | **Vulnerability and capacity focus** |
| Single agency | → | **Whole-of-society** |
| Separate responsibility | → | **Shared responsibility of health systems** |
| Response-focus | → | **Risk management** |
| Planning for communities | → | **Planning with communities** |

### 1.2.3 The Health ERDM Framework: Vision and Expected Outcome

The vision of Health EDRM is the "highest possible standard of health and well-being for all people who are at risk of emergencies, and stronger community and country resilience, health security, universal health coverage and sustainable development" *(7)*.

The expected outcome of Health EDRM is that "countries and communities have stronger capacities and systems across health and other sectors resulting in the reduction of the health risks and consequences associated with all types of emergencies and disasters" *(7)*.

Health EDRM is founded on the following set of core principles and approaches that guide policy and practice *(7)*:

- risk-based approach
- comprehensive emergency management (across prevention, preparedness, readiness, response and recovery)
- all-hazards approach
- inclusive, people- and community-centered approach
- multi-sectoral and multidisciplinary collaboration
- whole-of-health system-based and
- ethical considerations

Health EDRM comprises a set of functions and components that are drawn from multi-sectoral emergency and disaster management, capacities for implementing the IHR (2005), health system building blocks and good practices from regions, countries and communities *(7)*. The Health EDRM Framework focuses mainly on the health sector, noting the need for collaboration with many other sectors that make substantial contributions to reducing health risks and consequences.

Health EDRM functions are organized under the following components *(7)*:

**Policies, strategies and legislation:** Defines the structures, roles and responsibilities of governments and other actors for Health EDRM; includes strategies for strengthening Health EDRM capacities.

**Planning and coordination:** Emphasizes effective coordination mechanisms for planning and operations for Health EDRM.

**Human resources:** Includes planning for staffing, education and training across the spectrum of Health EDRM capacities at all levels, and the occupational health and safety of personnel.

**Financial resources:** Supports implementation of Health EDRM activities, capacity development and contingency funding for emergency response and recovery.

**Information and knowledge management:** Includes risk assessment, surveillance, early warning, information management, technical guidance and research. This recognizes the need for these capacities to be strengthened to support risk/needs assessments, disease surveillance and other early warning systems, and public communications with the aim of ensuring that “the right information gets to the right people (including communities, practitioners and decision makers) at the right time” and the role of research in supporting the evolution of evidence, knowledge and practice and the development of new interventions and innovative risk management measures.

**Risk communications:** Recognizes that communicating effectively is critical for health and other sectors, government authorities, the media, and the general public.

**Health infrastructure and logistics:** Focuses on safe, sustainable, secure and prepared health facilities, critical infrastructure (such as water and power), and logistics and supply systems to support Health EDRM.

**Health and related services:** Recognizes the wide range of health-care services and related measures for Health EDRM.

**Community capacities for Health EDRM:** Focuses on strengthening local health workforce capacities and inclusive community-centered planning and action.

**Monitoring and evaluation:** Includes processes to monitor progress towards meeting Health EDRM objectives, including monitoring risks and capacities, and evaluating the implementation of strategies, related programmes and activities.

The Health EDRM Framework recognizes that information and knowledge management capacities are crucial for effective Health EDRM. This includes the ability to support risk assessments and other forms of needs assessments (Chapters 2.2 and 3.1), disease surveillance and other early warning systems (Chapter 2.4), and public communications (Chapter 4.11). It also seeks to ensure that the collection, analysis and dissemination of information is harmonized across relevant sectors. This requires good quality research, with evidence-based technical guidance to build capacity through training programmes and health systems improvements.

## 1.2.4 The WHO Thematic Platform for Health EDRM Research Network

In 2018, WHO established the WHO Thematic Platform for Health EDRM Research Network (Health EDRM RN) in order to promote global collaboration among academics *(6–7)*, government officials and other stakeholders so as to generate better scientific evidence to inform policy and practice for managing health risks associated with emergencies and disaster. In 2017, leaders of this emerging research network published review papers on the Sendai Framework implementation and recommendations on Health EDRM research *(8–9)*. These highlighted the critical importance of conducting research before, during and after emergencies and disasters, and not only in the acute phase. Some key themes emerged from the research network's deliberations, including:

- the need for a holistic approach to Health EDRM to ensure that physical, mental and psychosocial health and well-being are addressed;
- identifying populations at risk with specific health needs;
- standardization of needs assessments, standardization of evaluation methodologies and reporting systems for countries, communities and individual cases;
- multidisciplinary and multi-sectoral approaches; and
- a review of research for informing better policy development and implementation.

There was also recognition of the need to reflect the variety of hazards that relate to Health EDRM (Table 1.2.2).

**Table 1.2.2 Truncated WHO Classification of Hazards *(7)***

| Groups | Sub-groups | Examples of main types |
|---|---|---|
| **Natural** | Geophysical | Earthquake, geophysical-triggered mass movement, tsunami, volcanic activity |
| | Hydrological | Flood, wave action, hydrometeorological-triggered mass movement |
| | Meteorological | Storms, cyclones, extreme temperature |
| | Climatological | Drought, wildfire |
| | Biological | Air-, water-, and vector-borne diseases, animal and plant diseases, food-borne outbreaks, antimicrobial resistant microorganisms |
| | Extraterrestrial | Meteorite impact, space weather |
| **Human-induced** | Technological | Industrial hazard, structural collapse, fire, air pollution, infrastructure disruption, cybersecurity, hazardous materials (including radiological), food contamination |
| | Societal | Armed conflict, civil unrest, financial crisis, terrorism, chemical, biological, radiological, nuclear, and explosive weapons |
| **Environmental** | Environmental degradation | Erosion, deforestation, salinization, sea level rise, desertification, wetland loss/degradation, glacier retreat/melting |

To accelerate research in Health EDRM, WHO organized a meeting to identify key research gaps and questions, bringing together leading experts from WHO, the World Association for Disaster and Emergency Medicine (WADEM) and Japan International Cooperation Agency (JICA), and delegates to the Asia Pacific Conference on Disaster Medicine (APCDM). The meeting was organized by WHO Kobe Centre for Health Development as one of the programmes during the Asia Pacific Conference on Disaster Medicine, on 17 October 2018, in Kobe, Japan *(10)*. One of the outcomes of that meeting was recognition of the need to produce guidance on research methods for those who need to use this research, and those who might be responsible for commissioning or conducting research in the future *(11)*.

### 1.2.5 WHO and research

Research and innovation are vital to WHO as a knowledge-based, normative and standard-setting organization. WHO hosts special research programmes, coordinates multi-country research, and supports research capacity development. It also benefits from over 800 WHO collaborating centres, which are institutions designated by the Director-General to carry out activities in support of WHO's international programme of work. Critical research functions have already been addressed and integrated into relevant strategic priorities: for example, research and development in support of access to and prequalification of medicines for UHC, and coordinating research for emergencies including the development of diagnostics, vaccines and therapeutics for epidemic-prone diseases. Research also forms a foundation for strategic shifts – in conjunction with diplomacy and advocacy, with normative guidance and agreements being based on the best science and evidence. WHO draws upon a wide range of disciplines, from the social sciences to implementation research, and uses its comparative advantage in respect of identifying needs and translating knowledge in order to facilitate research best conducted in research institutions.

WHO also helps to develop and scale up innovative solutions. Innovation can accelerate attainment of the SDGs and the goals in WHO's 13th General Programme of Work. WHO uses various approaches to achieve this: science and technology, and social, business or financial innovation. WHO's most effective role is as a facilitator, addressing barriers to innovation and acting as a "champion of champions" for innovation. WHO also works with partners to identify and coordinate the research, development and innovation needed to better detect, prevent and respond to new and emerging diseases and other hazards that endanger health.

### 1.2.6 The role of research in Health EDRM

People working in Health EDRM must face many topics about which there is uncertainty. In considering these, it is important to note that the UN General Assembly adopted the definition of disaster risk as "the potential loss of life, injury, or destroyed or damaged assets which could occur to a system, society or a community in a specific period of time, determined probabilistically as a function of hazard, exposure, vulnerability and capacity" *(12)*.

Uncertainties may arise from limited knowledge, understanding, access to or application of evidence, or the lack of evidence to support decision making and action. This may include uncertainty as to how common problems are, how to reduce the risks of those problems occurring and how to alleviate them if and when they do occur – questions that can be answered through the types of research described in other chapters. Evidence, supported by good quality research, is vital to helping resolve these uncertainties. Without evidence to support their decision making, decision makers run the risk that their actions will do more harm than good.

In some cases, the necessary research may have already been done and is brought together in systematic reviews and guidelines (Chapter 2.7), which can be used to inform decision making and action. Such guidelines must be prepared using rigorous systematic methods and the methods for producing high quality guidelines are now clearly described in, for example, the WHO Handbook for Guideline Development *(13)*. In some cases, practitioners and policymakers in Health EDRM will be able to rely directly on those guidelines, with current examples including the WHO Guideline on Communicating risk in public health emergencies *(14)* and WHO Housing and health guidelines *(15)*. Such guidelines should be underpinned by systematic reviews of existing research evidence (Chapter 2.6) and those producing the guidelines might draw on the output of international organizations dedicated to the production and maintenance of these reviews, such as Cochrane, the Campbell Collaboration and the Joanna Briggs Institute, or organizations, such as Evidence Aid, that collate systematic reviews to produce collections on specific topics, such as malnutrition *(16)* (Chapter 3.7).

In some areas of Health EDRM, research has already had a substantial impact on decision making, influencing the implementation of effective interventions or the avoidance of ineffective ones, thus improving the health and well-being of individuals and populations. For instance, research brought together in systematic reviews has identified:

- the benefits of vaccination to prevent common diseases *(17)*;
- strategies to improve water quality *(18)*;
- drugs to ease pain *(19)* ways to treat wounds *(20)*; and
- the potential harms of interventions such as brief debriefing to prevent post-traumatic stress disorder (PTSD) *(21)*.

Additional examples are featured as case studies in the chapters that follow.

However, in many cases, decision makers will be faced with an absence of existing systematic reviews or a lack of relevant studies of sufficient quality *(22)*. In these cases, they may need to work with researchers, and collaborators interested in doing research, to design and conduct their own studies *(23).* This book provides guidance on this process by outlining:

- research management processes that will lead to effective and efficient research studies;
- the value of a systematic approach to designing, conducting, reporting and using research;

- how to ensure that research is reliable, robust and fit for purpose, and meets the priority needs of those who will use it; and
- how to implement a research plan and translate its findings in routine, day-to-day practice, policy and programme direction setting.

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## 1.3

# Historical developments in Health EDRM policy and research: the case study of Japan

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### 1.3.1 Learning objectives

To understand the importance of research evidence for Health EDRM policy and practice, considering Japan as a case study, in order to be able to:

1. Review historical examples of disaster impact and response relevant to health.
2. Discuss how changes in health risks and resilience affect disaster impacts, and how disasters affect health risks.
3. Explain improvements in the methods used to assess and minimize health impacts of disasters.

## 1.3.2 Introduction

Disaster risk, which is defined as "the potential loss of life, injury, or destroyed or damaged assets which could occur to a system, society or a community in a specific period of time, determined probabilistically as a function of hazard, exposure, vulnerability and capacity" *(1)*. This definition of risk can apply to all types of hazardous events, including emergencies and disasters. These events are the outcome of the conditions of risk, that is the interrelationship between hazard, exposure, vulnerability and capacity, that are present in a community. This relationship can be expressed as follows:

$$Risk \propto function\ (hazard, exposure, vulnerability, capacity)$$

Disaster risk management relates to efforts to either reduce the hazards, exposure and vulnerability, increase the capacities, or do both.

As a disaster-prone country, Japan has developed a disaster risk reduction (DRR) policy and programme to manage the risks of the large-scale disasters it has experienced through its history, which include earthquakes, tsunamis, typhoons, floods and volcanic eruptions. Although the occurrence of a natural hazard largely depends on geographical and climate conditions, the impact of an event depends not just on the event's magnitude, but also on vulnerabilities and socioeconomic conditions such as poverty and social development *(2)*. Poor infrastructure and limited disaster risk management lead to higher numbers of deaths, injuries and illnesses in the affected population *(3–6)*.The amounts of missing and out-of-date data that reflect the social development and stability of each community should be considered when calculating the overall risk *(2, 7–8)*.

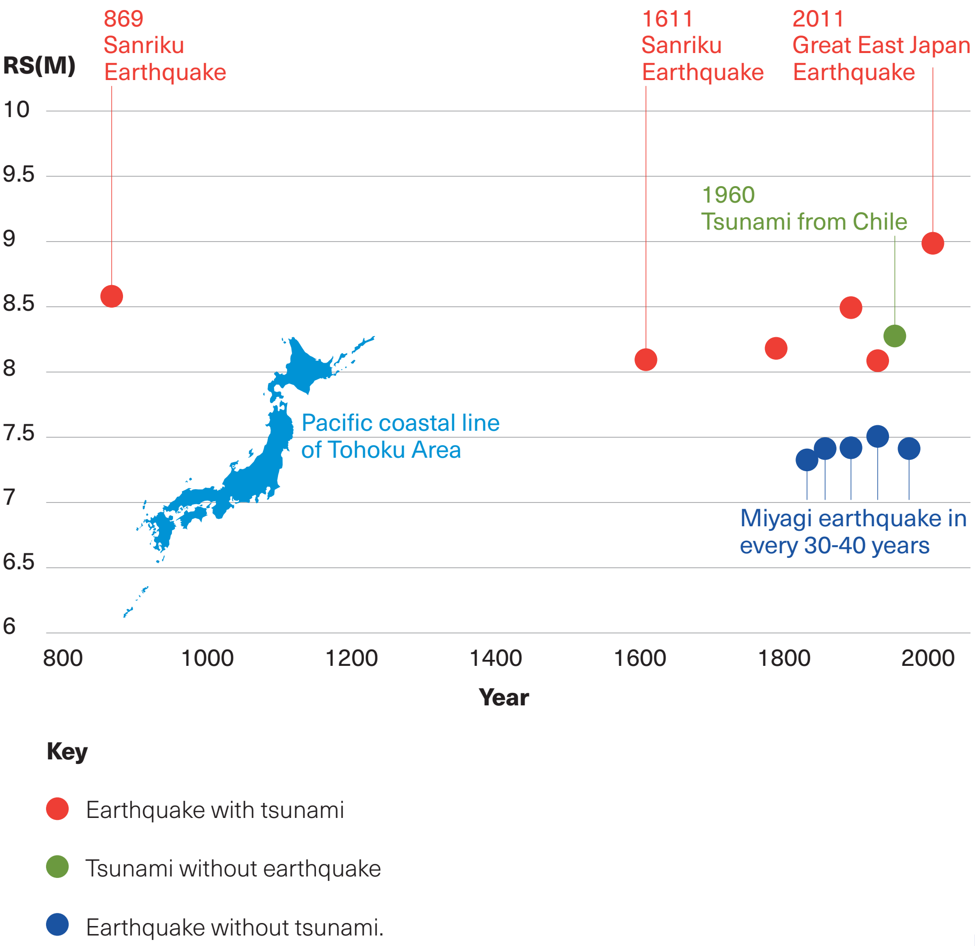
After the onset of a disaster, communities need to put an enormous effort into response, recovery, rehabilitation and reconstruction, as well as into reducing risks and anticipating or preparing for the next hazard event. These cyclical events can spiral into higher levels of risk and worse situations in future unless the aim of "Building Back Better" is achieved, but will worsen if this fails. Research and investment in Health EDRM provide an important means of identifying and managing the risk through these spiral cycles of disasters, and so are identified as priorities in the Sendai Framework *(9)*.

This chapter shows how the environment for conducting Health EDRM research has improved in Japan as a result of historical events *(10)* (see Case Study 1.3.1), and with the transformation and expansion of the country's disaster medical system (see Case Studies 1.3.2 to 1.3.7). These experiences are also relevant to policy and programme development in other countries.

## Case Study 1.3.1
## Using the history of disasters to understand disaster risk

Japan has a long history of preserving documents: the oldest historical record of a tsunami is from the 869 Sanriku Earthquake at Japan Trench, with an estimated magnitude of 8.6 *(11)*. The affected area, Tohoku in the northeast of Japan, has since been affected by several more earthquakes and tsunamis, including the 1611 Sanriku Earthquake, and has experienced magnitude 7 earthquakes every 30 to 40 years. In addition, the 1960 Valdivia Earthquake in the Republic of Chile led to a tsunami that killed 142 people and affected nearly 150 000 more in Japan (Figure 1.3.1). These level 2 tsunamis occur every 400 to 800 years, and evacuation has usually been the only way to survive *(12)*. More recently, the region has improved its risk management of earthquakes and tsunamis, by building earthquake-proof housing and longer and taller sea walls, and by drawing on community tradition to educate people to evacuate after strong shaking. Although the 2011 Great East Japan Earthquake resulted in more than 20 000 deaths and displaced 480 000 people, the level of vulnerability reduction and capacity building was not in vain. For instance, seismic-proof buildings that did not collapse and high seawalls, such as that in Taro Town, Iwate Prefecture *(13)*, along with early warning systems and the tradition of self-evacuation behaviour *(14)* all helped to reduce the number of victims.

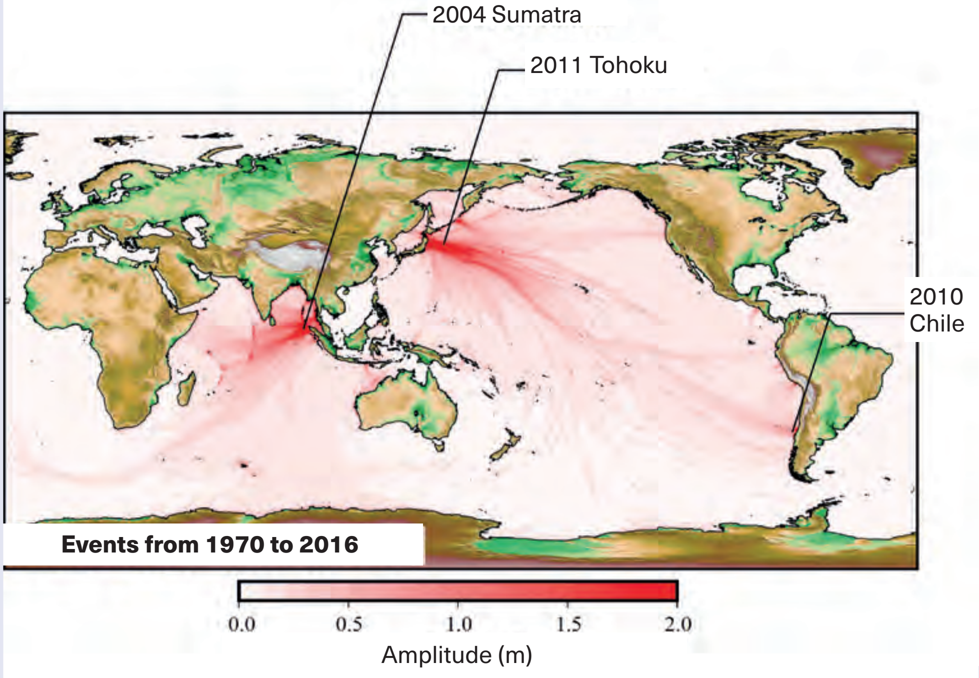
**Figure 1.3.1 History of earthquakes and tsunami in the pacific coastal line of Tohoku area, Japan**



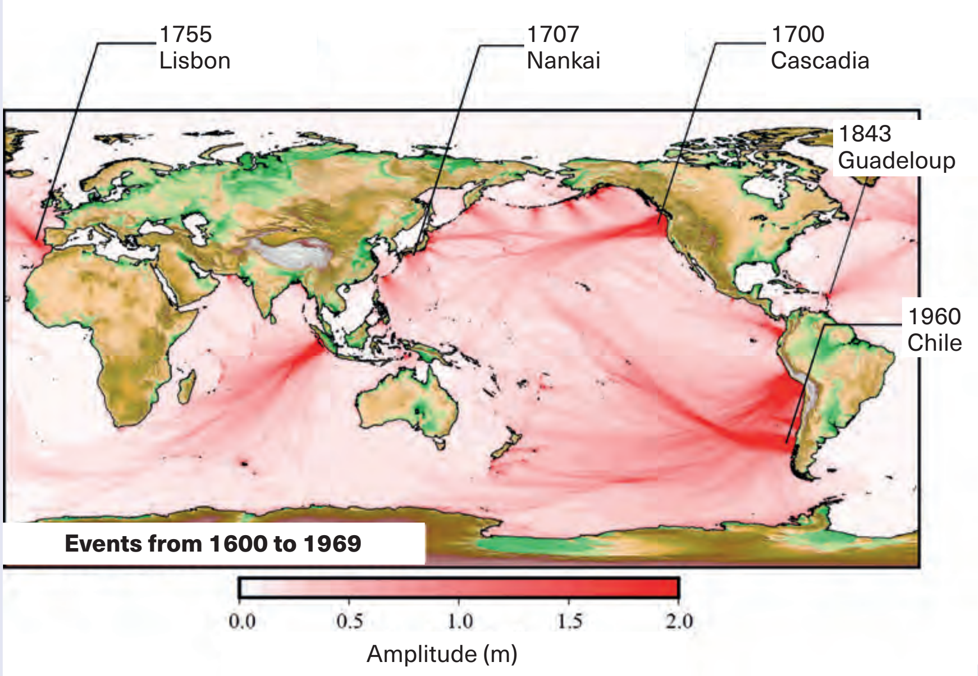
Although tsunamis occurred only in the western Pacific and Indian Ocean from 1970 to 2016, (Figure 1.3.2-A), in the 370 years from 1600 to 1969, major tsunamis had occurred in all areas of the world (Figure 1.3.2-B). This shows the importance of assessing and understanding hazards via historical events, and not relying solely on recent experiences.

**Figure 1.3.2 Simulated maximum tsunami amplitude (adapted from *(15)*)**

A: 1970 to 2016 (47 years)



B: 1600 to 1969 (370 years)



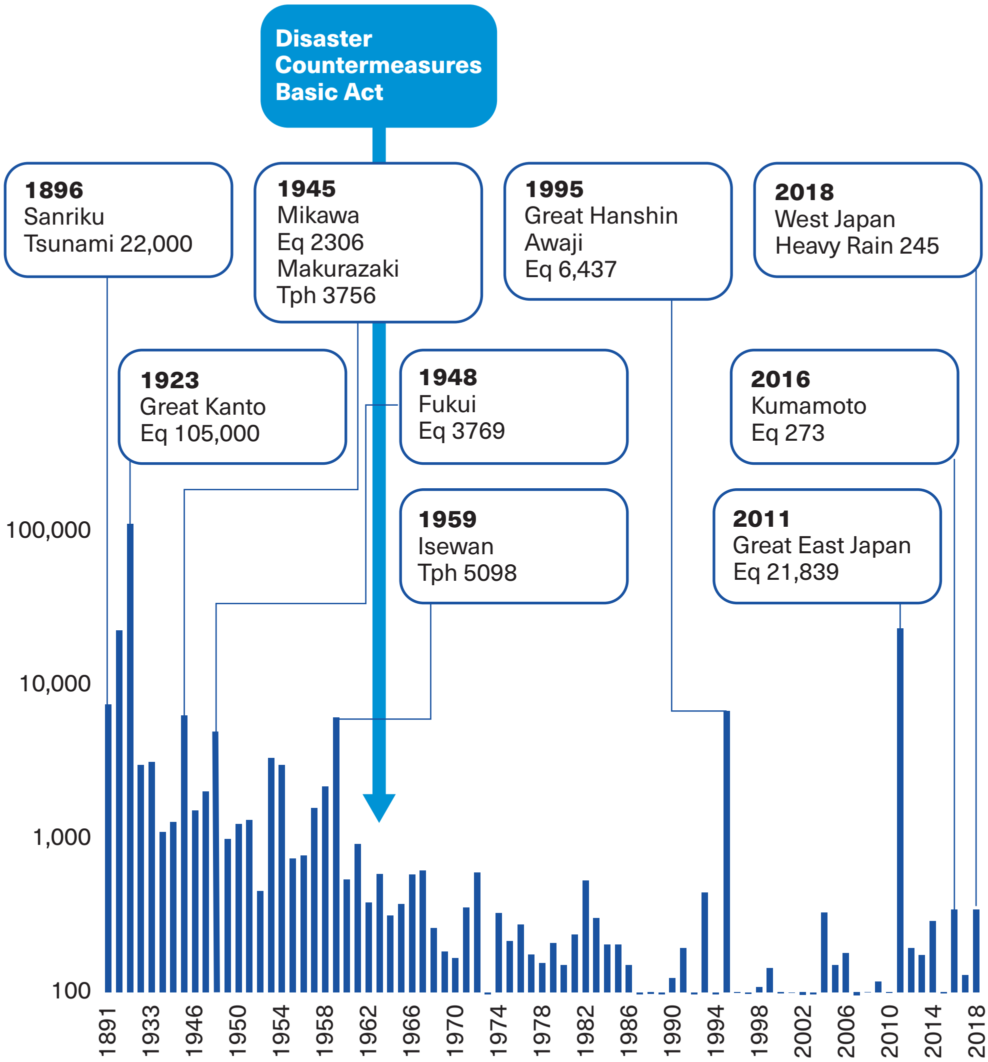
### 1.3.3 Large-scale disasters prompt policy changes to address health needs

On 1 September 1923, the Great Kanto Earthquake struck the Tokyo metropolitan area and more than 100 000 people were trapped in collapsed buildings or killed by fire. As a consequence, the building code first enacted in 1920 was modified in 1924 to triple the mechanical safety factor. After World War II, Japan experienced several earthquakes and typhoons that killed thousands of people (Figure 1.3.3), leading the Government of Japan to establish the Disaster Countermeasures Basic Act in 1961 (Act No. 223 of 15 November 1961; revised June 1997) and to develop comprehensive and systematic disaster risk management as a national priority *(16)*. Under the Disaster Countermeasures Basic Act, the Government of Japan prepares an annual report, the White Paper, which provides an overview of disasters in Japan, various statistical data and disaster management measures taken by the Government *(17)*.

The building code was revised again several times during the twentieth century, to include regulations to increase lateral seismic coefficient, strengthen reinforced concrete, and set allowable unit stress and horizontal load bearing capacity using evidence from surveillance and research on damaged buildings in earthquakes. After many buildings collapsed in the 1995 Great Hanshin Awaji Earthquake, the current version of the building code was enacted in 2000, requiring buildings to be able to endure at least one violent shake.

The building standard for nuclear reactors was established in 1981 and further modified in 2006. This requires nuclear reactors to be fixed to firm rock bed and countermeasures for possible tsunami inundation. After the 1979 Three Mile Island nuclear power plant incident in the United States of America (USA), the Japan Nuclear Safety Committee established the Disaster Measure around Nuclear Power Plant (Nuclear Emergency Response Guideline) in 1980. Then, after the 1999 Tokaimura critical nuclear incident, that guideline was revised and renamed “Disaster Measure around Nuclear Facility” in 2000. The Nuclear Regulation Authority enforced the current Nuclear Emergency Response Guideline in 2013, after the 2011 Great East Japan Earthquake and Fukushima nuclear power plant incident *(18)*.

## Figure 1.3.3 Number of deaths in natural disasters in Japan



**Key:** Eq: earthquake, Tph: Typhoon.
The number of deaths in the 1995, 2011 and 2016 earthquakes include disaster-related deaths. Adapted from White Paper of Disaster Management *(19).*

On 17 January 1995, the Great Hanshin Awaji Earthquake (magnitude 7.3) struck the densely populated Kobe City and surrounding area. It caused 6437 deaths and injured nearly 44 000 people, and led to the concept of "preventable disaster death", which is defined as "death occurring during a disaster that would have been preventable under normal conditions of regional health systems" *(20)*. Analyses of the deaths found that 83.3% resulted from crush injuries due to the collapse of buildings and 12.8% were from burns *(22)*. This highlighted the main medical needs in the acute phase (within three days after the onset of the disaster), which were for the treatment of trauma, such as crush syndrome, and severe burns *(22–23)*. However, meeting these needs was especially difficult because 97.8% of the 180 hospitals and 84.0% of the 1809 clinics were damaged *(23)* (see Case Studies 1.3.2 to 1.3.4).

### Case Study 1.3.2
### Development of disaster nursing support system

The widespread damage to medical facilities caused by the 1995 Great Hanshin Awaji Earthquake meant that many hospitals and clinics were unable to function. Nurses were one of the main frontline health workers to provide medical support to survivors, but they were also greatly affected by the earthquake themselves. In order to provide the necessary surge capacity, the Japan Nursing Association (JNA) called on volunteer support nurses from across Japan and sent hundreds of nurses to the affected area. The Japan Nursing Association collaborated with Hyogo Nursing Association and the College of Nursing Art and Science Hyogo to coordinate the matching and allocation of volunteer nurses, based on the health needs of local communities. Volunteer nurses were sent to hospitals, elderly care homes and evacuation shelters to serve vulnerable populations, to screen for health problems among evacuees and to improve hygiene in the evacuation shelters.

Following this experience, the Japan Nursing Association established the volunteer nurses dispatching system for the response to disasters. Local nursing associations provide training to nurses willing to support this system and, once they qualify, register them as a Disaster Support Nurse. This system has worked well in several large-scale disasters, including the 2004 Niigata Chuetsu Earthquake, when 400 nurses were dispatched and the 2011 Great East Japan Earthquake, when 3770 nurses were dispatched *(24)*.

To support this initiative by the Japan Nursing Association, Japanese academia has developed disaster nursing capacity building. A national survey in 2005 found that approximately one in nine Nursing Schools in Japan had an independent subject of disaster nursing and 46% included disaster nursing as a part of other subjects *(25–26)*. Globally, the International Council of Nurses (ICN) and WHO have developed the International Council of Nurses Framework of Disaster Nursing Competencies *(27)*, which is being used to educate and train nursing students and professionals around the world *(28)*.

### Case study 1.3.3
### Development of an acute mental health support system

Since 1995, the Government of Japan has organized annual workshops for disaster mental health, including treatment for Post-Traumatic Stress Disorder (PTSD), which have been attended by 12 000 mental health professionals. Each local prefectural government appointed the participants to contact when there is a need for mental trauma care in an emergency situation. The Government also tasked the National Center for Neurology and Psychiatry with developing a national guideline for community mental health treatment in disasters. This states that most psychological symptoms after a disaster are natural, common and transient reactions; that psychological debriefing was not proven to be effective for preventing PTSD, and that Psychological First Aid (PFA) was the most recommended psychosocial counter measure immediately after a disaster. The guideline was distributed to every local government in

Japan as a basic national principle for the management of post-disaster mental health and has been translated into Thai and Indonesian.

In Japan, under the Disaster Relief Act, it is the governor of an affected local government who is responsible for requesting assistance and rescue from central and other local governments. Since 1995, this has included the dispatch of mental health care teams, composed of psychiatrists, nurses, psychologists, social workers and clerks, who usually rotate over one or two weeks. In the 2011 Great East Japan Earthquake, 57 teams including 3419 members were sent to disaster areas, and worked in close collaboration with the local prefectural and municipal mental health and welfare centres *(29–30)*.

### Case Study 1.3.4
### Development of a long-term mental health support system

As well as establishing a system for acute-phase mental health response after disasters, Japan has also developed a long-term mental health support system for survivors of large-scale disasters (*31–32)*. In response to the need for mental health support among the survivors of the 1995 Great Hanshin Awaji Earthquake, a traumatic stress care centre was established five months after the earthquake and the Disaster-Affected People Assistance Programme was implemented. This provided nearly 21 000 mental health consultations including more than 17 000 outreach visits and nearly 5000 group activities for survivors during its first five years. In 2004, the centre was reorganized as the Hyogo Institute of Traumatic Stress, becoming the first institute in Japan specializing in PTSD treatment, research and training *(33)*.

Building on the work of this centre, mental health care centres for long-term psychosocial support were also established following the 2004 Niigata Chuetsu Earthquake, the 2011 Great East Japan Earthquake and the 2016 Kumamoto Earthquake. The mental health care centre for the 2004 Niigata Chuetsu Earthquake provided more than 9000 consultations for more than 16 000 survivors in ten years. Three mental health care centres were established after the 2011 Great East Japan Earthquake; in Iwate, Miyagi and Fukushima. In collaboration with local municipalities and local academia, each centre has provided specialized care and support based on local needs, including outreach support, in-house consultation, mental health support for healthcare providers, advocacy for local communities and capacity building. These initiatives also enabled long-term follow up of people at risk of mental health disease, providing important data for research, such as that discussed in Chapters 2.1 and 5.1.

### 1.3.4 The National Disaster Medical System

The experiences of the Great Hanshin Awaji Earthquake described in Case Studies 1.3.2 to 1.3.4 prompted Japan to initiate its National Disaster Medical System. This comprises four components to enhance surge capacity for health response during and after disasters, which are shown in Table 1.3.1.

**Table 1.3.1 Components of the Japanese National Disaster Medical System**

| | |
|---|---|
| **Disaster base hospital** | As of May 2019, 743 tertiary hospitals (with multiple hospitals in each of the 47 prefectures in Japan) are designated as disaster base hospitals, with the following requirements:<br>- Seismic-proof structure<br>- Emergency supply of power, water, medical gas<br>- Emergency department, intensive care unit and heliport.<br>- Business continuity plan (added in April 2019)<br>Disaster base hospitals provide a centre of disaster response in the designated area and host a Disaster Medical Assistance Team (DMAT), composed of its employees, to support affected hospitals. Outside of disasters, disaster base hospitals provide education in disaster medicine to health professionals. The recently added requirement for a business continuity plan aims to strengthen emergency power, water and medical supply based on experience in recent disasters that caused disruption of basic service. All disaster base hospitals had implemented a business continuity plan by August 2019 *(34)*. |
| **Disaster Medical Assistance Team (DMAT)** | DMATs are teams of specially trained medical professionals comprising up to five members, including medical doctors, nurses and logisticians, who are able to work together using a single car. As of April 2017, there are more than 1500 teams registered across all prefectures in Japan. In principle, a DMAT would arrive at the affected area within 24 to 48 hours, under the command and control of DMAT headquarters. DMATs assist affected hospitals, health and welfare facilities, municipal headquarters and manage Staging Care Units (SCU) for wide area transportation, including hospital evacuation. DMAT members update their knowledge and skills through periodic training *(35)* and their education programme was revised after the 2011 Great East Japan Earthquake to focus more on communication, coordination and hospital support, including hospital evacuation *(36)*.<br>The initial concept of DMAT was developed in the USA, and the Japanese version of DMAT and Emergency Medical Information System (EMIS) have been implemented in many medical facilities *(37)*. |
| **Staging Care Unit (SCU) and wide area transportation** | To reduce the number of preventable disaster deaths, Staging Care Units (SCU) are used to select patients who will be transported to non-affected areas. SCUs are often based at an airport close to the affected area and support coordination between medical responders and transportation agencies. The role of SCU with limited resources can be flexible according to the situation *(36–38)*. |
| **Emergency Medical Information System (EMIS)** | EMIS is used to share real-time information among fieldworkers, headquarters and central government. It collects, frequently updates and shares information about the function of disaster base hospitals and other hospitals in the affected area, the status of evacuation centres, field hospitals, DMATs, and road and airport conditions for transportation. The updated headquarters activity plan and record are also shared through EMIS *(37–38)*. EMIS was updated after the 2011 Great East Japan Earthquake to incorporate a geographical information system (GIS) (see Chapter 4.8) in order to allocate the hospitals, clinics, welfare centres and DMATs in real time on a single map to improve efficient data sharing and decision making. |

The Japanese National Disaster Medical System improved the health response to disasters and was successfully implemented in several large-scale disasters after its establishment. However, the Great East Japan Earthquake on 11 March 2011 (magnitude 9.0) that affected a wide area of northeast Japan, causing many tsunamis over 10 meters high and leading to 22 252 deaths and 6233 injured people, identified further health needs, especially in relation to the care of vulnerable populations.

As of October 2011, of 380 medical facilities in the three most affected coastal prefectures (Iwate, Miyagi, Fukushima), 191 had totally or partially lost their ability to have in-patients and 205 facilities were completely or partially unable to accept out-patients. Ten facilities were completely destroyed and 290 facilities were partially destroyed *(21)*. The large size of the affected area, the wide variety of population needs and the range of assistance available made clear the need for disaster medical coordinators *(39)*. For instance, disruption to haemodialysis as a result of loss of electricity and water was an emergent threat to life, and so the network of medical doctors related to haemodialysis collaborated successfully with DMAT to organize the large-scale evacuation of 80 haemodialysis patients from the Kesennuma area of Miyagi Prefecture to Hokkaido and 581 patients from the Fukushima Prefecture (154 to Niigata, 382 to Tokyo and 45 to Chiba), providing temporary dialysis before transfer if necessary *(40)*. This led to the inclusion of haemodialysis liaison as an additional component of the National Disaster Medical System.

In the acute phase after the earthquake, particular challenges included providing support for damaged psychiatric hospitals and ensuring safety, food and medicine for hundreds of their hospitalized patients. Although some mental health professional teams voluntarily supported the affected areas, effective support was difficult to implement because of the lack of clear reporting lines or collaboration agreements *(41)*. In response to the need for mental health support for affected people and damaged facilities, the Disaster Psychiatric Assistance Team (DPAT) was established in 2013 *(42–43)*.

Government facilities and the public health workforce were also severely damaged in the 2011 Great East Japan Earthquake. A total of more than 140 000 person days were provided by external local municipality officials to support the affected areas, but the damage to facilities and the loss of officials meant that the host municipalities lost much of their management and coordination capability and could not effectively allocate or utilize the limited resources *(44)*. Therefore, to address the surge needs for public health and logistical management, Disaster Health Emergency Assistance Teams (DHEAT) were developed.

In addition, further health needs, including evacuation support and follow-up rehabilitation for disabled people and the need for special consideration and follow up for maternal and child health were also highlighted in the management of evacuations. These and other follow-up activities resulted in the development of the Japan Disaster Rehabilitation Assistance Team (JRAT) and Mother and Child Health Liaison.

Another of the significant gaps during the 2011 Great East Japan Earthquake was the lack of any standard medical record form for emergency medical teams. Teams from different organizations used different forms, making it difficult for them to share clinical information. This failure in continuity of care led to the creation of the Joint Committee for Disaster Medical Record of Japan, which proposed a standard disaster medical record form *(45)*. A special feature of this standard recording format is its inclusion of a daily medical report function called J-SPEED (see Table 1.3.2 and Case Study 1.3.5).

The earthquake also highlighted the concept of "disaster-related death" *(46)*. According to the Government of Japan's Reconstruction Agency, as of 21 August 2012 some 1950 people who had initially survived the earthquake and tsunami were confirmed dead due to disaster-induced fatigue, psychological trauma or the aggravation of existing chronic diseases. This concept was further highlighted in the 14 April 2016 Kumamoto Earthquake (magnitude 6.5) where nearly 80% of deaths (218 out of 273, as of 12 April 2019) fell into this category *(46)*. As a consequence, the SPHERE standard *(47)* is increasingly applied to the environmental improvement of evacuation shelters and to the lives of affected people to try to reduce these deaths that are not directly caused by the disaster.

Along with the developments in health response to disasters in Japan described above, there have also been important innovations to improve preparedness for better health response in the acute phase (Case Study 1.3.5) and research to increase health resilience in affected areas (Case Studies 1.3.6 and 1.3.7).

## Table 1.3.2 Additional components of the Japanese National Disaster Medical System introduced after the 2011 Great East Japan Earthquake

| | |
|---|---|
| **Disaster medical coordinators** | Disaster medical coordinators are officially appointed by prefectures and coordinate the activities of external and internal medical assistance teams to maximize their impact on the medical and public health needs of affected populations through close communication with local stakeholders. Following an initial initiative in Hyogo Prefecture after the 1995 Great Hanshin Awaji Earthquake, by 2011 only four prefectures had designated a disaster medical coordinator but, by 2015, 43 out of 47 prefectures (91%) had designated or were planning to designate such a coordinator *(39)*. |
| **Disaster Psychiatry Assistance Team** | Disaster Psychiatry Assistance Teams (DPAT) assist psychiatric hospitals and support surge mental health needs in affected areas after disasters by assessing the local psychiatric needs and collaborating with DMAT and other assistance teams and local psychiatric facilities to provide high quality psychiatric medicine *(43)*. With the support of the DPAT Secretariat, DPAT members update their knowledge and skills through periodic training *(44)*. |
| **Disaster Health Emergency Assistance Team** | Disaster Health Emergency Assistance Teams (DHEAT) assist the management function of the public health sector in affected local municipalities, through information collection, integration, analysis and sharing with fieldworkers. Local municipalities (prefectures, special assigned cities and political areas) are recommended to organize Disaster Health Emergencies Assistance Teams with public health professionals *(48-50)*. The operation plan has been developed since 2014 and has been available on the Ministry of Health, Labour and Welfare website since March 2018. Sixteen local municipalities dispatched Disaster Health Emergencies Assistance Teams to the areas affected by the 2018 West Japan Heavy Rain *(44).* |
| **Japan Disaster Rehabilitation Assistance Team** | Japan Disaster Rehabilitation Assistance Teams (JRAT) assist, in particular, older people and people with disability from the very early phase of evacuation. JRATs promote conversation with evacuated people, set up slopes and handrails in the evacuation centre or in temporary houses, and provide care and supervision. JRATs also provide temporary support devices and aids to promote rehabilitation of affected people. |
| **Mother and Child Health Liaison** | Paediatricians and obstetricians join the disaster medical headquarters team to coordinate mother and child health issues, including perinatal care and mental and physical support of children. |
| **Haemodialysis Liaison** | Physicians network to identify people who need haemodialysis in the affected area and coordinate their transportation to areas outside the affected region. This can include the provision of transitional temporary haemodialysis before patients are sent to more distant hospitals *(40)*. |
| **Standard disaster medical record /J-SPEED** | The disaster medical record has been standardized and all emergency medical teams use it regardless of their organization. This makes it easier to transfer clinical information among medical providers for continuity of patient care. One special feature of this standardization is a daily medical report function called J-SPEED (see Case Study 1.3.5). |

### Case Study 1.3.5
### Development of health data management systems

Timely and effective data collection during and after a disaster is key for better health response (see Chapter 4.4) and is a large challenge for national Emergency Medical Teams (EMTs) such as DMAT *(51)*. Having experienced these problems after the 2011 Great East Japan Earthquake, a joint committee was established and started a project to develop a standardized format for medical data collection to support effective information collection, sharing and analysis for the following response. This format was developed with reference to the Surveillance in Post Extreme Emergency and Disaster (SPEED) system, developed by WHO and the Ministry of Health of the Philippines *(52)* (see Chapter 2.2).

The newly developed format, referred to as the Japanese version of SPEED (J-SPEED) includes health conditions such as certain chronic diseases, which are more common in Japan *(53)*. It was successfully used by all national EMTs during recent disasters in Japan, including gathering medical data from 8089 consultations during the 2016 Kumamoto Earthquake, 3620 consultations during the 2018 West Japan Heavy Rains and 591 consultations during the 2018 Hokkaido earthquake. It enabled rapid assessment of the health needs of affected people and significantly contributed to the identification of people who required referrals to specialist teams, acute mental health support (who were referred to DPAT), and other specific health responses *(54)*.

This progress has taken place alongside the development of the WHO Emergency Medical Team (EMT) Minimum Data Set (MDS), a standardized medical data collection and reporting system adopted in 2017.

### Case Study 1.3.6
### Cohort studies to evaluate longitudinal effects of a disaster on affected communities

Many cohort studies have been designed and conducted to evaluate longitudinal effects of the 2011 Great East Japan Earthquake on the affected communities. These studies were established as a collaborative effort between local governments and academic institutes in the affected regions to better understand the health condition of residents. Care and follow-up activities were undertaken to improve the health condition of the affected communities based on the outcome of the surveys.

For example, the Fukushima Health Management Survey is conducted by the Fukushima Prefectural Government and the Fukushima Medical University to alleviate residents' concerns over radiation and facilitate appropriate health care of residents in the Fukushima Prefecture. The surveys assess longitudinal health conditions of people who lived in the Prefecture between 11 March and 1 July 2011 *(55-56)*.

As another example, the Center for Community Health was established in Tohoku University to assess the longitudinal effect of the earthquake on affected communities in Ishinomaki city, Shichigahama town and Sendai City *(57)*. The Shichigahama Health Promotion Project was designed and conducted as a collaboration between Shichigahama town and Tohoku

University. The project team conducted annual surveys and follow-up of all residents whose houses suffered major damage *(58)*.

Knowledge accumulated from these activities can be useful not only for improving the health of residents affected by this specific disaster, but also for reducing exposure and vulnerability, disaster preparedness, response to, and recovery from future disasters. Similarly, using the same or a similar format for the collection of health information for people affected by future disasters will support research consistency and should facilitate ethical approval (see also Chapters 3.4 and 6.4).

### Case Study 1.3.7
### Long-term follow up using registers and biological data

Tohoku University is one of Japan's leading national universities  and is located in the area affected by the 2011 Great East Japan Earthquake. It initiated the Tohoku Medical Megabank Project in order to restore community medical services in the areas heavily damaged by this earthquake and tsunami disaster, and to establish an advanced medical system to meet the global trend towards large-scale medical information technology. The project is executed in corporation with Iwate Medical University and funded by the national Government of Japan.

The earthquake caused catastrophic damage not only to health facilities but also to the health workforce in the Tohoku District. While the reconstruction of health facilities was implemented relatively successfully with support for infrastructure reconstruction, there was a notable decline in the number of medical professionals in Tohoku. This became alarmingly severe in more recent years and recruiting health professionals to work in the re-constructed medical facilities became critical. This urgent need led to a unique project to develop a centre of future-oriented medical services in Tohoku and to make this a driver for attracting medical practitioners.

Through the Tohoku Medical Megabank Project, an integrated biobank was established of biospecimen and information from cohort studies focused on the effect of the disaster on health *(59)*. There are two initial cohort programmes in the Tohoku Medical Megabank Project: (i) the Birth and Three-Generation Cohort Study and (ii) the Community-Based Cohort Study. Both are predominantly targeting the earthquake-affected areas and consist of multiple components including genomic studies. Along with assessment of the effects of the disaster, participants in these studies can contribute to other independent biomedical research to address knowledge gaps relating to differences between those with and without the same illness who lead the same lifestyle, and differences between individuals who are responsive or non-responsive to various forms of exposure. Several reports from the project have already clarified the influence of the disaster on vulnerable populations *(60)*. This project has enabled the long-term follow up of biomedical aspects of disaster-affected people, as well as promoting large-scale research more generally, which will use the voluntary contributions of the study participants to address other areas of uncertainty.

In Japan, the national Government's disaster management policies are decided by the Central Disaster Management Council, which is chaired by the Prime Minister and includes all Cabinet members. During and after a large-scale disaster, the Cabinet Office is engaged in the collection and dissemination of accurate information, reporting to the Prime Minister, establishment of the emergency activities system (including the Government's Disaster Management Headquarters), and the overall wide-area coordination of disaster response measures. DRR has been carried out using the concept of "Building Back Better" through consultation with scientific experts to help with prediction of hazards, assessment and reduction of exposure and vulnerability, and building of response capacity *(17)*.

Improvements to the National Disaster Medical System is a key part of DRR. Research into Health EDRM is promoted by a grant-in-aid from the Japanese Society for Promotion of Science, Ministry of Education, Culture, Sports, Science and Technology (MEXT) and the Ministry of Health, Labour and Welfare of Japan, while the budget for implementing countermeasures and response comes from the Cabinet Office. Awareness of these mechanisms for research promotion and implementation among researchers is also promoted in order that science and technology can be used to enhance DRR.

### 1.3.5 Conclusions

The long history of large-scale disasters in Japan and the substantial events of recent decades have provided the country with many opportunities to learn from the past to improve Health EDRM for the future. This has made use of evidence from research of many different types, and has led to the implementation of the National Disaster Medical System. This has continued to be refined as new evidence has accumulated, helping to ensure that disaster risk management, including prevention, preparedness, response and recovery, make an important contribution to the health of the nation, and encouraging partnerships between policy makers, practitioners and researchers to lead to further improvements in the future.

### 1.3.6 Key messages

- **Health EDRM requires the continual enhancement of policies and programmes using both historical evidence and up-to-date, reliable, scientific evidence from research. This requires high-quality research, which needs capacity building in research methods and timely, accurate and appropriately collected data.**
- **This chapter featured Japan as an example of applying the principle of Building Back Better through its spiral cycles of disasters. The development of health systems and the health workforce over time in response to the health needs identified in emergencies and disasters has improved data collection, assisted the management of survivors and produced a better environment for research and subsequent policy making.**
- **This chapter illustrates how policy development and the enhancement of health systems have built on evidence from before, during and after emergencies and disasters in Japan, and provides a practical example for other countries.**

## 1.3.7 Further reading

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**Disaster Medical Needs and Responses in Japan**

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# Identifying and understanding the problem

# 2.0

# 2.1

# Using epidemiological principles to assess impacts of emergencies and disasters

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## 2.1.1 Learning objectives

To understand how data can be gathered for epidemiological research in emergencies and disasters in order to assess the risk factors and health consequences, including:

1. Sources of vulnerability and exposure to hazards.
2. Impacts of disasters on mortality and morbidity.
3. Sources of data and databases that are available for epidemiology research.
4. Value of surveillance mechanisms for epidemiological studies of disasters.

## 2.1.2 Introduction

To adequately describe a disaster, or any other significant health event, requires some quantification of the scale of its impact on humans and society at large: we need to describe how people's health is affected by such events and analyse the causes of those effects. Without this understanding of the problem, we are not equipped to develop targeted measures – in health and other sectors – to reduce risks before, during and after emergencies.

Epidemiological studies can help us with this by investigating the distribution and determinants of health or disease. Epidemiological studies may also identify ways to prevent diseases and other health problems at source, to control them or to mitigate their effects. Ideally, studies should investigate the long-term impacts of disasters, but this is rare, with most studies focusing on the immediate effects (typically those during the first year).

Applying the principles of epidemiology to the study of the determinants and the effects of disasters on human populations is crucial. It provides some of the evidence base for effective health emergency and disaster risk management (Health EDRM), and it includes assessment of the adverse health effects of disasters, analysis of the risk factors that affect exposure and vulnerability to hazards, and of the capacities of individuals, communities and institutions to manage these risks. The aim of such analyses is to inform preparedness and response efforts, recovery strategies and – crucially – to help to explain, predict and mitigate the consequences of future disasters by allowing the development of targeted measures to prevent and reduce hazards as well as the exposures and vulnerabilities of populations at risk.

Epidemiology is a vital tool for situational awareness, which in disaster settings provides much needed information to allow the identification of population needs, plan a response and gather appropriate resources. The main objectives of disaster epidemiology are therefore:

- to prevent or reduce the number of deaths, illnesses, and injuries caused by disasters;
- to provide timely and accurate health information for decision-makers and practitioners to improve risk assessments, prevention, mitigation, preparedness, response and recovery strategies;
- to provide a fundamental body of evidence on the health impacts of disasters that can be used for research and evaluations *(1).*

WHO estimates that, in the last decade, more than 2.6 billion people have been affected by disasters such as earthquakes, tsunamis, landslides, cyclones, heat waves, floods, or severe cold weather *(2)*. This chapter outlines some of the methods that may be used to arrive at such a figure and to study the factors that contribute to this burden.

Disasters may lead to displacement of populations, disruption to health systems and damage to health infrastructure. Each of these has consequences for public health, including increased mortality, deteriorating mental health, outbreaks of infectious diseases and acute malnutrition. Such consequences are all more severe when people are living in high density, frequently temporary settlements with insufficient food, water, housing or sanitation *(3–5)*. Furthermore, displaced people are at increased risk of violence, including sexual and gender-based violence.

A range of expertise is needed to manage the risks of a variety of public health problems. These include specialists in vaccine-preventable and other infectious diseases, water, sanitation, and hygiene (WASH), nutrition, injury, sexual health, and mental health — as well as leaders, managers, emergency service personnel, risk communicators, logisticians, and evaluators in health and other sectors. Identifying the different health impacts of disasters and the causes of these impacts may require a similarly broad range of methods. Using epidemiological principles to underpin surveillance for research in disaster settings is largely contingent on recognizing opportunities when they occur to collect actionable information that can be used for developing or evaluating interventions to preserve health and save lives (for example, identifying the first cases of measles or diarrheal disease in a camp).

Epidemiological assessments might involve analysing risk factors and studying health outcomes, but the tasks required for this are rendered especially complex because of the involvement of many different agencies, using non-aligned data collection systems. Furthermore, data may be collected, collated or stored at some distance from the location of the initial disaster. These challenges need to be considered carefully when designing an epidemiological study — and are discussed in this chapter. Some of the key techniques for disaster epidemiologists include assessments of need (which may require rapid assessment), health surveillance, the use of registries of affected individuals and assessment of outbreaks and other cascading hazards that may follow the initial event.

### 2.1.3 Rapid needs assessments

One of the key pieces of epidemiological research to undertake — and one that is normally applied in a sudden-impact emergency and disaster situation — may be to assess the immediate impact on the health of the affected population and their consequent healthcare needs.

Rapid needs assessments employ survey and population sampling methods to determine the health status and basic needs of those in the area affected by a sudden-impact disaster. The use of appropriate sampling provides epidemiological rigour and a rationale on which to base planning, operational response and resourcing decisions. Care must be taken to ensure that the population sampled is truly representative of the wider population for whom the findings will be extrapolated. Furthermore, because limited comprehensive information is typically available on the consequences, scale and severity of the disaster at the time of impact, the use of reliable epidemiological methods may be important in preventing undue reliance on data gathered by responders who may be working independently or without coordination. Nonetheless, the purpose of the rapid needs assessment is to provide an opportunity to collate what data might be available, even if such informal data gathering may result in assessments that are incomplete, conflicting or unreliable.

One of the survey tools that might be used to gather data for epidemiological research is the Multi-Cluster/Sector Initial Rapid Assessment (MIRA). This was developed by the Inter-Agency Standing Committee (IASC)'s Needs Assessment Task Force (NATF) and is an example of a system to facilitate a rapid needs assessment. It seeks to address the problem of conflicting findings from needs assessments conducted by different crisis responders within and between sectors *(6)*.

A MIRA can be carried out jointly by key stakeholders in a short period of time (days or weeks) and aims to provide a foundation of commonly understood information about the affected population and their needs. It may also support the identification of information sources in the early stages of the process, which can be used to support prioritization of the humanitarian response and immediate development of a strategy through three components:

i) The systematic collation and analysis of secondary data, which may initially be the only information available and which were collected for other reasons — epidemiological methods can be used to analyse these data in order to describe the extent of the disaster, the number of affected people and places, and allow articulation of immediate priorities, bearing in mind the identified hazards and risk factors.

ii) Community level assessment, which is a standard approach for collecting and analysing new or primary data — this allows agencies to integrate the needs and priorities of affected communities into the broader assessment of strategic humanitarian priorities. Such community level assessments are limited to those communities that can be found or accessed and as such must be considered in the context of the secondary data analysis noted above.

iii) Collation and analysis of all data and information following an agreed structure, which analyses and describes the primary and secondary data obtained by all agencies or responders.

### 2.1.4 Health and health facility surveillance

Many countries have their own national or regional systems for health surveillance, which are vital during outbreaks, disasters from natural and technological hazards, and conflicts. In public health, this surveillance includes the systematic collection, analysis and interpretation of health-related data for the planning, implementation, and evaluation of public health practice. Such surveillance can serve as an early warning system for an impending outbreak, help target response efforts, document the impact of an intervention, monitor and clarify the extent of health problems and allow priorities to be set and public health policy and strategies to be implemented based on quantitative evidence. For example, surveillance of vaccine-preventable diseases, such as measles, is vital for managing a potential outbreak, as well as in disaster or conflict settings, in order to understand the functioning of the wider health system and recognize weaknesses early.

Disasters and other complex emergencies often increase the risk of transmission of infectious diseases and make other health problems (such as severe malnutrition) more likely. An effective disease surveillance system is essential to detecting disease outbreaks quickly before they become difficult to control. However, if the routine system is adversely affected by the impact of the disaster or is not designed to gather information relating to the health consequences of the hazards that led to the disaster or arise in its aftermath, a more specialized system may be needed.

A recent example of the development of one such specific surveillance tool is WHO's Early Warning, Alert and Response System (EWARS) (see Case Study 2.2.1). This was designed to improve disease outbreak detection in emergency settings, such as in countries experiencing an outbreak in another part of the country, in conflict or following a disaster caused by natural hazards *(7).*

'EWARS in a box' was developed by WHO to strengthen the gathering of health data in outbreaks, disasters and other emergencies, and may provide an important means of gathering the data needed for epidemiological research. It is an emergency kit containing the equipment needed to rapidly establish early warning, alert and response activities, particularly in difficult and remote field settings without reliable internet or electricity. It has been used across the world, including in the response to cyclone Idai in the Republic of Mozambique in 2019 *(8).*

The box contains 60 mobile phones, laptops and a local server to collect, report and manage disease data. A solar generator and solar chargers allow the phones and laptops to be powered without mains electricity. Each health facility can be allocated a mobile phone with a disease reporting app that will allow health workers to enter data on patients with symptoms of priority diseases or conditions such as acute diarrhoea, cholera, measles, acute flaccid paralysis, fever, malaria and jaundice. The app uploads the information to a server, where the data is used to generate real-time reports. This allows a rapid response to emerging diseases as well as allowing aggregated reports from health facilities, automatic triggering and investigation of alerts, collation of lists of all known and suspected cases (line lists) during outbreaks and recording of verification and risk assessment activities.

Where possible, health surveillance should rely on existing systems and processes as, when these are functioning, they can provide the most reliable and timely information (*9–10*). Such systems gather information on a routine basis from hospitals, primary care settings and laboratories, but may need amendments or augmentations to enable them to rapidly detect diseases of the highest priority and consequence in a disaster, which may differ markedly from those the systems were established to detect.

Healthcare surveillance systems make it possible to measure demand for services and identify where emergency or other healthcare resources may become stretched or overrun. Syndromic surveillance systems (see Chapter 4.9), such as England's National Ambulance Surveillance System, can be used to reveal early information about unfolding incidents and outbreaks *(11)*. Monitoring of calls to poison centres may allow identification of public exposure or concern about chemicals or other environmental hazards *(12)*.

However, although such systems may be a feature of high-income countries, they may not be in place in some low- and middle-income countries, or they may be particularly susceptible to the impact of disasters on staffing and infrastructure. For example, recurring outbreaks in the African region have led to recognition of the need for outbreak response tools that can be implemented during complex emergencies when existing national public health surveillance systems may be underperforming, disrupted or non-existent. Existing national public health surveillance systems may quickly become overwhelmed and unable to meet the surveillance information needs of a large-scale outbreak, conflict or disaster. In addition, existing tools may not be sufficiently comprehensive, or address requirements in the field during emergencies, which can lead to proliferation and fragmentation of data collection at the frontline. This can make it especially important for those designing epidemiological research to take particular account of the quality of the data, and decide whether the data from routine health and health facility surveillance systems is sufficiently reliable.

To illustrate how epidemiological research needs to use methods that supplement routine data, Case Study 2.1.1 describes how a variety of epidemiological studies were used to estimate the number of deaths caused by Hurricane Maria in Puerto Rico.

### Case Study 2.1.1
### Mortality estimates from Hurricane Maria in Puerto Rico

Puerto Rico is a part of the USA in the northeast Caribbean Sea, with a population of approximately 3.3 million.

Hurricane Maria, a category 4 hurricane, hit Puerto Rico on 20 September 2017. Widespread damage affected the healthcare system and caused power outages. By the end of 2017 the number of deaths was estimated as 64 *(13)*, but this only considered deaths for which a “hurricane related” cause of death was recorded on the person’s death certificate. Although this would be a standard epidemiological technique for using routine data to determine the number of deaths due to a specific cause, this method of measurement may be unreliable in the disaster context.

For example, a study published in May 2018 *(14)* estimated the number of excess deaths to be close to 6000, with most of these deaths resulting from the interruption of services such as health care, electricity, and water access. This epidemiological study gathered its data through a household survey, extrapolated the household mortality rate to the complete population and compared this to the mortality rate for the same period in 2016.

In a subsequent study *(15)*, data from before Hurricane Maria were used to estimate an average number of expected deaths per month. This generated a conservative estimate of 1139 excess deaths, with levels returning to the pre-hurricane range by December 2017, three months after the hurricane.

Finally, an independent review commissioned by the government used the official, national statistics to estimate the total excess number of deaths after the disaster. This reported that there were 1427 more deaths in the four months after the hurricane than the number expected using data from the previous four years *(16)*.

These different ways of estimating the number of deaths caused by the hurricane illustrate the potential impact of using different techniques for epidemiological research. They vary from counts based on death certificates in the immediate aftermath of the hurricane to estimates based on comparisons with the same months in previous years. This is important when considering the implications of epidemiological research — the updated estimate from the government-commissioned review prompted the government to undertake a major review of its preparedness, which should help to inform future planning and the public health preparation and response to such a disaster in the future.

### 2.1.5 Outbreak investigations and other incident reports

Outside the context of disasters from natural hazards, conflicts and other emergencies, epidemiological methods are used to investigate disease outbreaks, employing both descriptive and analytical techniques to understand the source of a disease or infection, how it may be spreading and how best to control it. This may allow interventions to be put in place to prevent further morbidity and mortality. These studies include assessments of the prevalence of biological and pathogenic hazards and of the health consequences already known to be caused by them, as well as investigations that test the association between hazards and health outcomes to investigate whether these hazards lead to the health outcomes.

These epidemiological methods can also be important in disasters from natural hazards where, for example, population movements or damage to healthcare infrastructure can lead to the more rapid spread of infectious diseases. Epidemiological studies can use exposure data to determine the presence of these risk factors and assess the effects of an intervention. For example, case control studies in the Republic of Haiti in 2012-14 found that a reactive cholera vaccination programme provided protection from four to 24 months after vaccination. This was important because vaccination is a key component of efforts to control cholera epidemics *(17).*

In some cases, investigations may take place long after the acute disaster phase, as health impacts and the research needed to investigate them may take some time to be identified. For example, epidemiological techniques such as case control and cohort studies were employed to look for risk factors for traumatic injury after an earthquake in California. These longer term studies found that peak ground acceleration, perceived shaking intensity, building characteristics, and individual characteristics were important risk factors for injury *(18–19).*

Case Study 2.1.2 provides an example of how epidemiological methods were used to study long-term environmental contamination and the outbreak investigation mechanisms needed to determine cause and effect, as well as the control systems that had to be put in place.

**Case Study 2.1.2**
**Minamata Bay and organic mercury poisoning**

Between 1932 and 1968, it was reported that an estimated 27 tons of mercury was released into Minamata Bay *(20)*.

In the 1950s, initial reports of poisoning involved local cats, birds and fish *(20)*. By the middle of the decade, symptoms started to appear in humans: these included loss of fine motor control, stumbling while walking, and violent tremors *(21)*. Using a wide range of epidemiological techniques including surveys, case interviews and descriptive and analytical epidemiological studies, a link was made with consumption of contaminated fish *(22)*.

Organic mercury was identified as the cause in 1959.

The findings of these studies contributed to a global treaty, the Minamata Convention on Mercury, seeks to protect human health and the environment from the adverse effects of mercury *(23)*.

## 2.1.6 Databases holding disaster data

Some of the epidemiological research relevant to emergencies and disasters is able to draw on data included in disaster databases. These present exciting opportunities for disaster epidemiology but also highlight some challenges. Despite containing large amounts of data from emergencies and disasters that can be analysed and reported, they reflect the shortcomings in the data itself. These include a lack of standardization in collection methodologies and definitions, and the absence of a single reliable source of verified data *(24)*. Moreover, the databases are hosted by a variety of organizations, with different disciplinary affiliations and scientific traditions. Individual databases are usually set up with distinct objectives, which may be inconsistent with those of other databases. This makes it difficult to compare outputs across databases, as has been shown in several comparisons *(25–26)*. This lack of a shared focus makes it difficult to come to a consensus on the range and magnitude of impacts and, as a result, to have confidence in the estimates presented *(27)*. Described below are two of the main disaster databases (EM-DAT, from CRED, and the Desinventar), followed by information on the Sendai Framework Monitor (SFM), which has recently been developed with the intention of providing a more complete and shared global database on disasters, aligned with the targets of the Sendai Framework for Disaster Risk Reduction 2015-2030 *(28)*.

### CRED and EM-DAT (Emergency Events Database)

The Centre for Research on the Epidemiology of Disasters (CRED) was established in 1973 as a non-profit institution, with international status under Belgian Law. It is located in the School of Public Health of the Université Catholique de Louvain in Brussels. In 1988, **CRED** launched the Emergency Events Database (EM-DAT). This widely used and cited database was until recently fully accessible to the public. It provides information on the human impact of disasters, including the number of people killed, injured or affected; as well as economic damage estimates and disaster-specific international aid contributions.

For a disaster to be entered into the database, at least one of the following criteria must be fulfilled:

- At least ten people reported killed
- At least 100 people reported affected
- Declaration of a state of emergency
- Call for international assistance.

EM-DAT contains core data on the occurrence and effects of more than 15 700 disasters from 1900 to present, including those caused by natural and technological hazards. The database is compiled from various sources, including UN agencies, non-governmental organizations, insurance companies, research institutes and press agencies. However, the eligibility criteria for EM-DAT mean that it does not include data on the large number of smaller events that occur each year that do not meet at least one of the four eligibility criteria. It is also hampered by the issues surrounding disaster data generally, namely the challenges of capturing data on all disaster events and the potential unreliability of data and reports on health impacts, including mortality.

### DesInventar: a Disaster Loss Database

In the early 1990s, groups of researchers, academics, and institutional actors in Latin America linked to the Network of Social Studies in the Prevention of Disasters in Latin America (Red de Estudios Sociales en Prevención de Desastres en América Latina - LA RED) worked together to develop DesInventar, a conceptual and methodological tool for generating National Disaster Inventories and constructing databases of information on damage, losses and other effects of disasters on specific countries. Subsequently, UNDP and UNISDR sponsored implementation of DesInventar in the Caribbean, Asia and Africa. Desinventar includes:

- Methodology (definitions and help in the management of data)
- Database with flexible structure
- Software for input into the database.

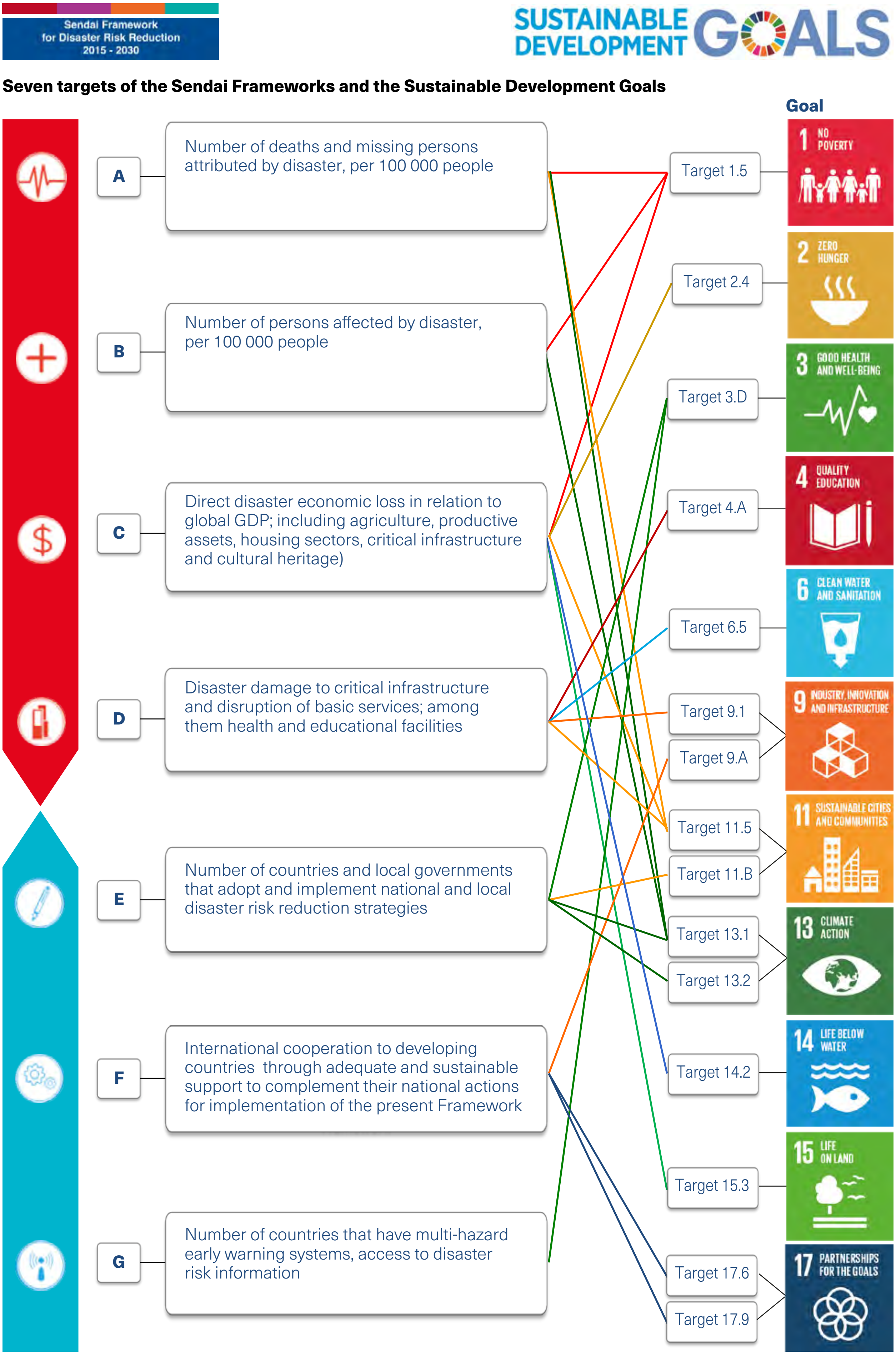
The information in DesInventar inventories is spatially disaggregated in order to show (and later analyse) the effects of disasters at a local level. The minimum disaggregation level recommended for country-level disaster inventories is equivalent to municipality, which is usually one or two levels below the country's first-level administrative or political division (province, state or department depending on the country). A list of the available databases from reporting counties is available on the DesInventar website and DesInventar has been linked to reporting for the Sendai Framework Monitor.

**Sendai Framework Monitor**
UNDRR has identified strong accountability as a corner stone of the Sendai Framework for Disaster Risk Reduction 2015-2030 *(28)*. A set of 38 indicators, recommended by an intergovernmental expert working group, are being used to track progress in implementing the seven targets of the Sendai Framework, as well as its related dimensions reflected in the Sustainable Development Goals (Figure 2.1.1). The Sendai Framework Monitor will also function as a management tool to help countries document their disasters, in order to facilitate their understanding of which disaster risk reduction strategies may be beneficial, assist in risk-informed policy decisions and inform the allocation of resources to prevent new disaster risks.

UNDRR is implementing a system to determine progress in implementing the Sendai Framework and this will be assessed every two years. As of March 2018, UN member states must use the online Sendai Framework Monitor to report against the indicators for measuring the global targets of the Sendai Framework. A detailed timeline has been developed and shared for the key milestones of the process and 84 of 195 countries had started to report as of August 2019.

The Sendai Framework Monitor is a major outcome of the Sendai Framework for Disaster Risk Reduction, which should provide more complete systematic information about the occurrence of all disasters, including those of small and medium impact. It should provide disaggregated data about the effects of large scale disasters that has not previously been available for most countries.

**Figure 2.1.1 Links between Sendai Framework reporting and the Sustainable Development Agenda**



**Seven targets of the Sendai Frameworks and the Sustainable Development Goals**

**A** Number of deaths and missing persons attributed by disaster, per 100 000 people

**B** Number of persons affected by disaster, per 100 000 people

**C** Direct disaster economic loss in relation to global GDP; including agriculture, productive assets, housing sectors, critical infrastructure and cultural heritage)

**D** Disaster damage to critical infrastructure and disruption of basic services; among them health and educational facilities

**E** Number of countries and local governments that adopt and implement national and local disaster risk reduction strategies

**F** International cooperation to developing countries through adequate and sustainable support to complement their national actions for implementation of the present Framework

**G** Number of countries that have multi-hazard early warning systems, access to disaster risk information

Target 1.5
Target 2.4
Target 3.D
Target 4.A
Target 6.5
Target 9.1
Target 9.A
Target 11.5
Target 11.B
Target 13.1
Target 13.2
Target 14.2
Target 15.3
Target 17.6
Target 17.9

### 2.1.7 Value of disaster epidemiology for research

Epidemiological research can be used to generate knowledge long after a disaster response effort has passed. It might help to fill evidence gaps that are identified by the evaluation of the response, as well as identify further gaps that need to be filled. Although many public health and other disaster responders may have no or few resources to commit to formal epidemiological studies or research, the role of initial needs assessments, surveillance and incident investigations is vital in informing the later strategy for knowledge generation. By using existing data from, for example, surveillance systems or disaster databases as mentioned above, researchers can minimize the research waste that might arise from them conducting their own data gathering, such as through new surveys. Researchers need to be part of collaborations between responding agencies, academic institutions, government agencies and funding bodies to help them to understand the benefits and shortcomings of using existing data and to identify priority areas for new research. These partnerships are critical to ensuring that opportunities to improve future disaster response are taken. By way of illustration, Case Study 2.1.3 shows how epidemiological research provided important evidence on the mental health impacts of flooding in the United Kingdom.

**Case Study 2.1.3**
**Measuring mental health impacts of flooding**

After widespread flooding in England in 2013-14, a multi-year National Study of Flooding and Health was established to examine the long-term impact of flooding on the mental health of people living in flood-affected areas.

The methodological complexities of measuring mental health impacts of flooding meant that collecting data on a range of personal factors was essential. A year after the flooding, the epidemiological research showed psychological morbidity was elevated among both flooded participants (prevalence of depression 20.1%, anxiety 28.3%, PTSD 36.2%) and those who were disrupted but without floodwater entering their homes (prevalence of depression 9.6%, anxiety 10.7% PTSD 15.2%) *(29)*. The prevalence of depression, anxiety and PTSD among unaffected respondents living in the same area were 5.8%, 6.5% and 7.9% respectively.

Furthermore, flooded participants who reported disruption to domestic utilities (such as electricity, gas or water) or to health care were more likely to have developed symptoms of one of these mental health problems than other flooded participants. For example, after adjusting for the depth and duration of floodwater in the home, the odds of probable depression were 1.7 times higher for participants who were displaced compared with those who were not *(30)*. The amount of warning received appeared to be a protective factor amongst those who were displaced, with those receiving no warning before flooding reporting more symptoms of depression and PTSD than those who were forewarned.

## 2.1.8 Conclusions

Public health research is essential in determining and understanding health impacts from disasters and other emergencies. Epidemiological research provides the evidence to help decision makers plan for future disasters, showing both the causes and consequences of hazards that cause disasters and arise from them. Key epidemiological techniques for disaster research include assessments of need, health surveillance, registries of affected populations and new studies into outbreaks and other cascading hazards that may follow the initial event. Tools such as the IASC NATF Multi-Cluster/Sector Initial Rapid Assessment (MIRA) and the WHO's Early Warning, Alert and Response System (described above) can contribute to reliable research in Health EDRM.

## 2.1.9 Key messages

- **The principles of epidemiology for emergencies and disasters are critical to understanding risk factors and health impacts of disasters and informing strategies for health emergency and disaster risk management.**
- **Disaster databases are important sources of data but have limitations that need to be recognized by researchers and it is hoped that the Sendai Framework Monitor will help overcome some of these problems**
- **Health impacts of disasters can be both immediate and long term; the long-term impact has been relatively under-studied and thus the burden on a population is likely to be under-estimated and inadequately addressed.**

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# 2.2

# Measuring the health impacts of disasters

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## 2.2.1 Learning objectives

To understand the following key factors relating to measuring the health impacts of disasters:

1. The importance and relevance of measuring the health impacts of disasters.
2. The variety of indicators that characterize the health impacts and risks of emergencies and disasters.
3. Systems and methodologies that can be used to measure health impacts.
4. Challenges and issues in measuring the health impacts of disasters.
5. Strategies to cope with these issues.

## 2.2.2 Introduction

Between 2008 and 2017, disasters from natural hazards registered in international databases affected, as an annual average, nearly 200 million people, causing nearly 70 000 deaths and leading to economic losses of more than US$ 160 billion *(1)*. A further 172 million were affected by conflict *(2)*. From 2012 to 2017, WHO recorded more than 1200 outbreaks, including outbreaks of new or re-emerging infectious diseases, in 168 countries. In 2018, WHO tracked 352 infectious disease events, including Middle East respiratory syndrome coronavirus (MERS-CoV) and Ebola virus disease. Given the tendency of international disaster data to focus on large-scale events, such data usually omit the large numbers of small- to medium-scale events that also have substantial health, economic, social and environmental effects *(2)*. Measuring the effects of emergencies and disasters and building systems that can facilitate in-depth investigation both of their causes and of their effect on people is imperative to enabling us to better reduce the risks of emergencies and disasters and their ensuing human impact.

Measuring the health impacts of disasters can help in determining the scale and scope of response needed, defining the 'big picture' operationally, quantifying the magnitude of urgent needs, ensuring the response is appropriate and timely, assessing progress, and allowing comparisons to be made among different emergencies and disasters. Epidemiology provides a good foundation for measuring, studying and using indicators that are critical to reducing risks in emergencies and disasters, and helping to ensure that health impacts and outcomes are measured systematically. Epidemiological methods may be used to characterize affected populations, especially vulnerable groups, and assess their vulnerability and exposure, as well as to quantify impacts and generate evidence for public health interventions before, during and after emergencies (See Chapter 2.1).

Public health decision-making for emergencies and disasters relies critically on information about the anticipated or actual health impacts of these events. The ability to measure health impacts should therefore be an integral part of any Health EDRM system. The development of capacities in public health surveillance, epidemiological investigation, laboratory testing and other related technical areas – responsibility for which belongs to the public health sector – supports measurement of the health impacts of disasters, which is crucial to being able to prevent, prepare for and respond to these events appropriately.

Indicators that can be used to describe the impacts of emergencies and disasters are an important area for study. Conventionally, such indicators are measured in terms of human impacts or fatalities, physical impacts through property damage and effects on critical infrastructure, as well as socioeconomic impact indicated by financial losses. Table 2.2.1 shows the indicators that can be used to quantify the impacts of sudden-impact disasters from natural hazards specifically in relation to health (see also Chapter 2.4).

### Table 2.2.1. Common health indicators used to quantify sudden-impact health impacts from natural hazards *(3)*

| Effect | Health indicator | Application |
|---|---|---|
| **Death** | Number of deaths among the population | Rough assessment of disaster severity |
| | Number of impact-related deaths among the population of a given age | Identification of vulnerable groups for further Health EDRM planning |
| | Number of deaths and number of houses destroyed | Assessment of building structure safety<br>Evaluation of predisaster community rescue training |
| | Number of impact-related deaths per unit of time after the disaster among the population | Evaluation of self-reliance of community |
| **Hospital admission** | Number of casualties among the population | Evaluation of predisaster prevention, mitigation and preparedness measures<br>Evaluation of warning adequacy |
| | Distribution of reasons for hospital admission | Estimation of emergency care available and relief needs<br>Identification of critical services to be maintained in emergency |
| | Hospital bed occupancy and duration of stay in hospital | Monitoring of health facilities and medical care needs |
| | Geographical origin of hospitalized patients | Needs assessment for relief supplies, including field hospitals |
| **Health-seeking behaviour** | Number of consultations among the surviving population | Estimation of type and volume of medical relief and resources |
| | Time distribution of consultations | Scheduling of medical relief |

To ascertain health impacts of disasters, it is useful to examine health impacts as a function of risks –that is, the probability and negative consequences of exposure of individuals, communities and the population to a wide range of hazards. Risks may be compounded by vulnerabilities intrinsic to individuals (such as extremes of age, weak immune status, strong familial history of disease) or characteristic of communities (low income level, low educational attainment, poor sanitary practices) and by limited capacities of health systems (weak governance, poor coordination mechanisms, suboptimal investments). Conversely, health risks and impacts can also be reduced by the capacities that can be built into the health system and other sectors at the individual, community and population levels.

### Case Study 2.2.1
### New technologies to detect and track outbreaks: Early Warning, Alert and Response System in the People's Republic of Bangladesh

Between late August and mid-December 2017, an estimated 655 000 Rohingya women, men and children fled to Bangladesh. In tackling an outbreak of diphtheria among the Rohingya refugees, WHO utilized both old and new public health tools. Contact tracing was used to find all the people who may been exposed to the disease. Diphtheria treatment centres were established to take care of those affected and keep the disease contained. A newly developed computer program known as the Early Warning, Alert and Response System (EWARS) allowed the quick collection of field data, geographical location and affected populations (see also Chapter 2.1). This allowed the response teams to act promptly. EWARS was developed by WHO specifically for humanitarian and emergency settings and is designed to be used by local people in at-risk communities. It works even without an internet connection.

The importance of surveillance systems in Health EDRM cannot be overemphasized. Public health surveillance applied to Health EDRM encompasses continuous, systematic collection, analysis and interpretation of disaster and health data crucial for planning, implementation and evaluation of public health interventions in emergencies and disasters. During emergencies and disasters, health assessments to measure health outcomes make it possible to determine needs and identify related services in the immediate, short and long term. Activation of surveillance systems, and use of relevant data are essential to Health EDRM. Case Study 2.2.1 provides an example of how such surveillance can help.

Although the value and benefits of measuring health outcomes are clear, emergencies and disasters by their very nature present numerous challenges to the functionality of surveillance systems. Starting with the physical effects of disasters on the affected communities, power and communication may be affected by the destruction of lifelines; critical infrastructure such as roads, bridges and airports might also be damaged. Health infrastructure such as hospitals, clinics, laboratories and public health offices might be damaged or destroyed, along with their equipment, materials and supplies. Disasters can also affect healthcare providers and those responsible for health surveillance. Other impacts include high population mobility as a result of displacement and the breakdown of other vital services and insecurity. All of these can constrain the effective, efficient and timely use of epidemiological data for evidence-based action in emergencies and disasters. Methodological issues can also arise because of the lack of baseline data or sample sizes that are too small to provide generalizable findings.

However, the most important challenge may be the resulting prioritization of emergency response and relief operations over assessment and measurement activities. This may mean that public health interventions are not guided by sound evidence, and further health risks may be realized instead of being prevented. However, it is possible to undertake both tasks at the same time, and this should be encouraged.

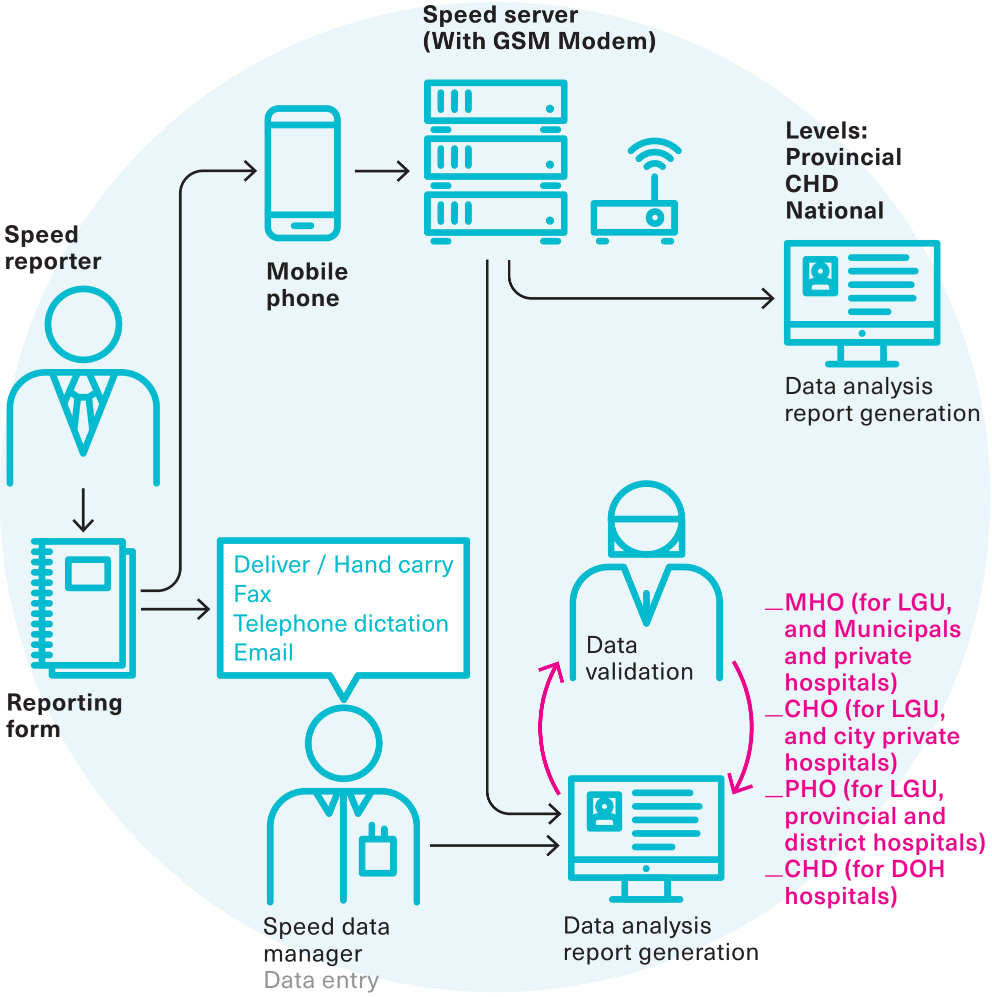
It is also important to evaluate the preparedness of public health systems to conduct real-time surveillance, and measure and count health outcomes and indicators during emergencies and disasters. In some low and middle-income countries, it may be difficult to organize and maintain surveillance and reporting systems. In some cases, baseline data may not be available, there could be significant variation in data that are collected, or it may not be possible to institutionalize surveillance systems because of insufficient technical capacity, or human resource or logistics issues.

### 2.2.3 SPEED in the Philippines

The Surveillance in Post-Extreme Emergencies and Disasters (SPEED) programme in the Philippines provides an illustrative example of an actual system used by public health authorities to measure and manage the health risks of a disaster to a population. SPEED is an early warning and alert system developed by the Department of Health in the Philippines, which was born out of the country's experience with a range of emergencies and disasters that caused a significant public health burden to the country (see Chapter 1.3 for a description of how a modified version of SPEED was used in Japan). Firstly, it describes the type of health issues emerging in the communities and in temporary shelters after huge population displacements, secondary to the disaster, across the timeline from post-disaster response to recovery. Secondly, it shows how SPEED as a system draws an "operational picture" of the disaster and so guides appropriate public health interventions to manage the health risks that have been measured. This highlights the critical function of such a system not only in measuring but also in managing these health risks. Lastly, this example brings to light some common issues encountered in utilizing the system in the context of emergencies, in order to underscore the importance of prevention and preparedness strategies that aim to build robust health information systems during normal times to support response when it is needed.

SPEED is an early warning surveillance system that monitors consultations for health conditions arranged in syndromes. It assesses health trends and uses web-based software that receives data via short messaging service (SMS) and converts data into customizable reports.

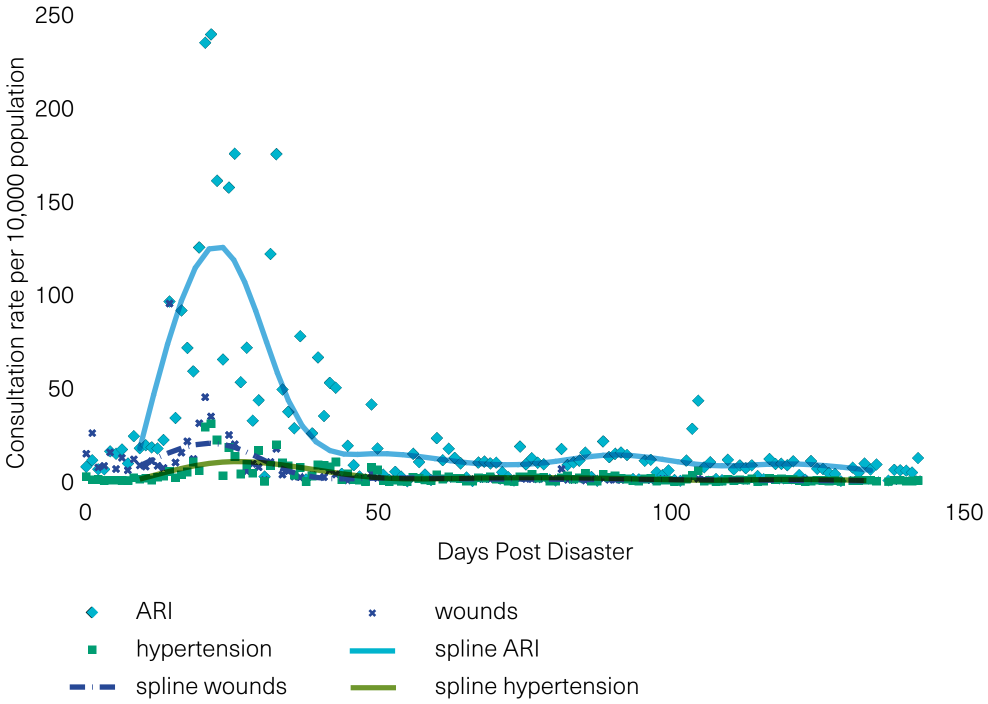
**Figure 2.2.1 The SPEED Reporting System** *(4)*



**Key:** MHO Municipal Health Officer; LGU Local Government Unit; CHO City Health Officer; PHO Provincial Health Officer; CHD: Center for Health Development; DOH Department of Health

In November 2013, Typhoon Haiyan – one of the strongest category typhoons ever to make landfall in the Philippines – ravaged six of the country's 17 regions. Strong winds, heavy rainfall and storm surges led to an unprecedented impact: 6300 dead, 1061 missing and 26 689 injured. The typhoon damaged all health facilities in its path, affected many healthcare workers and disrupted critical infrastructure (water, power, communication). This impaired the delivery of health services to the affected population. As soon as local and international emergency medical teams arrived and started to provide their services, SPEED was activated. The Department of Health prioritized SPEED after having seen the value of early warning systems after extreme events, and implemented it despite several obstacles (such as poor network and communication, lack of health human resources, logistical concerns), using the data and findings it collected to plan the response activities. This led to an analysis of health impacts and gave a clear picture of diseases that ensued in different timeframes. It showed that the most common morbidities were communicable diseases in children and injuries and non-communicable diseases in adults. Important public health interventions such as mass vaccination for vaccine-preventable diseases, logistics and medical supply augmentation for hypertension and diabetes were undertaken to decrease preventable morbidity and mortality after the disaster. SPEED data indicated that the focus of interventions should be on primary health care rather than specialist care, which helped in team deployment decisions. Furthermore, as well as depicting the severity and magnitude of disruption to the health system (which was fully apparent within two months after the typhoon), it delineated a recovery phase that signalled the transition of the health system from response to recovery. This guided the main recommendation to authorities that external medical teams were no longer needed, because local capacities were sufficient to address the long-term needs.

**Figure 2.2.2 Consultation rates per 10 000 individuals for acute respiratory infections, wounds, and hypertension in Typhoon Haiyan, Philippines, 2013 *(5).***



As reported by WHO, there was no outbreak of communicable diseases among the communities affected by Typhoon Haiyan. This was attributed to the contribution made by SPEED to facilitating early and appropriate actions and interventions that reduced health risks after the disaster.

SPEED was also used in the Zamboanga Siege in the Philippines in 2013. It demonstrated its usefulness as an early warning tool for disease prevention during this armed conflict situation on Mindanao Island.

### 2.2.4 Obstacles to implementation of SPEED during Typhoon Haiyan

Typhoon Haiyan destroyed or badly damaged many of the aspects of the health system that are crucial for measuring and counting (that is, epidemiology and surveillance). Hospitals, laboratories and public health offices were damaged, as were computers, mobile phones, reporting forms and other supplies. Lifelines (that is, communications, networks and power) were out of service for a week after the typhoon. Many healthcare workers were affected. Some were killed by the typhoon, some had their houses damaged, and some had family members or friends missing. Consequently, the routine surveillance system was paralyzed. Besides which, the immediate priority was to save lives, manage the dead and missing, and attend to the needs of the displaced population in evacuation centres, rather than measuring and counting health impacts. The Department of Health, aware of the value of SPEED, activated it. To circumvent problems with power and the communication network, it defaulted to the paper mode of SPEED, using manual documentation and processing. To address the shortage of healthcare workers, the Department of Health oriented and deployed international medical teams to gather SPEED data. It also sought the help of partners to report health data from the SPEED system.

The use of SPEED proved to be greatly advantageous in this context and subsequent enhancements were made. These included revision of criteria for activation and deactivation, inclusion of disease syndromes and revision of thresholds, updating of the format for SMS, revision of data entry and online reporting forms, and enhancement of maps and graphs.

It is also apparent that many predisaster strategies and systems are needed to support SPEED. For example, SPEED should be operationalized in such a way as to complement routine surveillance systems, as analysis of predisaster data and baseline information alongside SPEED data would provide a richer context for planning. There is also a need for continuous training to address the rapid turnover of SPEED-trained personnel. Software and hardware developments are also a priority in order to improve SPEED.

### 2.2.5 Conclusions

Measuring the diverse health impacts of different types of emergencies and disasters at health system, population and individual levels is critical in order to understand how people's health and health systems are affected by the interaction of hazards with their respective exposures, vulnerabilities and capacities. This understanding provides vital information to develop and implement Health EDRM strategies to reduce the risks and consequences of emergencies and disasters. The use of health trends in different post-disaster settings across time has helped guide public health managers in planning and implementing the response to, and recovery from, the affected population's varying health needs. The examples of WHO's EWARS and the Philippines' SPEED show the importance of measuring and managing the health risks of a disaster as an important public health function. Likewise, the examples show the effects of emergencies and disasters on the functioning of the health system and the need to make necessary adjustments and find solutions to address these challenges and assure continued functionality.

## 2.2.6 Key messages

- **Measuring the health impacts of disasters at health system, population and individual levels is critical in order to enable appropriate and timely public health interventions in emergencies and disasters.**
- **Various indicators should be measured to characterize the health impacts and risks of emergencies and disasters. Relevant data should be collected and analysed so that it can be used for various purposes and actions before, during and after emergencies and disasters.**
- **It is crucial to build capacities for epidemiology, laboratory testing, public health surveillance and information management as part of Health EDRM as these will provide the foundation for accurately measuring health impacts during emergencies and disasters.**
- **Although the effects of an emergency or disaster may make measuring health impacts particularly difficult, putting in place predisaster prevention and preparedness measures, operational readiness, back-up systems and contingency plans can prevent or overcome these obstacles.**

## 2.2.7 Further reading

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# 2.3

# Disease burden: generating evidence, guiding policy

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## 2.3.1 Learning objectives

To understand the basic concept of disease burden and its potential in identifying and understanding the health issues surrounding a disaster, in particular:

1. The strength of the burden of disease concept.
2. How to quantify the burden of disease from mortality and disability.
3. The content of three case studies using the burden of disease concept.

## 2.3.2 Introduction

A pivotal foundation to prioritizing policy planning and interventions for health emergency and disaster risk management (Health EDRM) is the availability of comprehensive and comparable evidence of mortality and disability, and the risk factors that may contribute to them (see Chapter 3.2). The burden of disease is a globally recognized concept that provides a methodological framework to quantify and compare population health using a summary measure of both mortality and disability: the disability-adjusted life year (DALY) *(1–2)*.

A major strength of the burden of disease concept is that it allows comparisons to be made between health losses due to mortality and disability, and those due to different diseases or injuries. DALY combines in one measure the time lost due to individuals' premature death from each disease or injury and the time lived with disability, taking into account the degree of severity of disability associated with different states of poor health caused by each disease and injury *(3)*. DALYs are therefore a useful measure for examining which diseases and injuries make the largest contribution to health loss in a given population group (by age, gender, location and so on) at a given time, as well as for identifying and understanding key health problems and prioritizing health policy concerns, such as resource allocation, interventions, service providing, research, and advocacy.

Disasters and hazards are major causes of injuries which lead to mortality and disability. The threat of both natural and human-induced health emergencies and disasters adds an even greater sense of urgency to the need to hasten efforts for risk management on an 'all hazards' basis *(4)*. Rapid and unplanned urbanization, along with climate change, widespread poverty and insecurity, social inequality, political instability, and economic stagnation, have all helped to increase the risks and harmful consequences of health emergencies and disasters. For example, more than 50% of the world's population now lives in urban areas, and this is expected to increase to 66% by 2050 *(5)*. These heavily urbanized areas are frequently also located in disaster prone regions, with 80% of the world's largest cities vulnerable to earthquakes and 60% at risk from storm surges and tsunamis *(6)*. Today, natural disasters cause annual economic losses of US$ 520 billion worldwide, and cause about 26 million people to fall into poverty *(7)*. Investing in disaster risk management can reduce the disaster impact in terms of both economic losses and burden of diseases, conserve resources, and protect development progress. Some studies have estimated that for every dollar spent on well-targeted and effective DRR, approximately US$ 7 will be saved from a reduction in economic losses *(8)*.

The adoption in 2015 of the Sendai Framework, the SDGs, and the Paris Agreement (with DRR interlinked between them) reflects national, regional, and global commitments to disaster risk management, presenting an unparalleled opportunity for action. The burden of disease concept is a powerful research tool in this context – for generating evidence, guiding policy, planning, and investing strategically on disaster risk management. This chapter provides a guide as to how DALYs are defined and calculated, describes their use in practice, gives a snapshot of the Global Burden of Disease Study (GBD) (the world's largest systematic, scientific effort to produce comparable estimates of disease burden), and concludes with three case studies illustrating how the burden of disease concept has been used in professional practice.

### 2.3.3 Quantifying the burden of disease from mortality and disability

The DALY measures the difference between the actual situation and an ideal situation in which everyone lives to the standard life expectancy and is in perfect health. DALYs associated with hazards as health risks include not only direct injuries and deaths, but also indirect health effects and their spillover effects due to the deterioration of health resources and social capital *(9)*. One DALY represents a one-year loss of 'healthy' life due to disease or injury. DALYs for a specific cause of disease or injury are calculated as the sum of the Years of Life Lost (YLL) due to premature death from that cause and the Years Lived with Disability (YLD) for people living in states of less than perfect health resulting from a specific cause:

$$\text{DALY} = \text{YLL} + \text{YLD}$$

The YLLs metric essentially corresponds to the number of deaths multiplied by the standard life expectancy at the age at which death occurs. The basic formula for YLL for a given cause, age, and gender is the following:

$$\text{YLL} = \text{N} \times \text{L}$$

where N denotes the number of deaths and L is standard life expectancy at age of death (in years). The standard life table (on which the standard life expectancy calculation is based) is a key component of the burden of disease concept. It corresponds to the ideal or aspirational life span for an individual in perfect health, but is not necessarily the actual life table of the population of interest. For example, a standard life table can be constructed from the lowest observed mortality rate in the latest year among all countries for each age and gender *(10)* or might be based on the life tables for countries with the highest longevity.

There are two methods of calculating the YLD for a particular cause in a particular time period: the incidence-based or prevalence-based approaches *(11)*. Prevalence looks at existing cases, while incidence looks at new cases. For incidence-based YLD, the number of incident cases in a given period is multiplied by the average duration of the disease or injury and a disability weight. This weight factor reflects the severity of the disease or injury on a scale from 0 (perfect health) to 1 (dead). The basic formula for incidence-based YLD is:

$YLD = I \times DW \times L$

where I denotes the number of incident cases, DW is the disability weight and L is average duration of the case to remission or death (in years). For prevalence-based YLD, the number of prevalent cases during a given period is also multiplied by a weight factor and the basic formula is:

$YLD = P \times DW$

where P is the number of prevalent cases and DW is disability weight. The disability weights for YLD are based on subjective measures. The conceptual and methodological basis for estimation of disability weights have been developed through various iterations *(12-14)*, and there is debate over their validity *(15-17)*. A large set of global disability weights estimated by the Global Burden of Disease and for the European population by Haagsma and colleagues can be found elsewhere *(13- 14)*. Further details of the methods used for estimating YLLs, YLDs, and DALYs are provided in the Global Burden of Disease study *(10, 18)*.

## 2.3.4 Use of DALYs in Health EDRM

By quantifying the burden of disease associated with health emergencies and disasters, DALYs are a valuable metric for setting disaster research and policy priorities. If the data allow, DALYs can be calculated for different socioeconomic groups (by gender and age group) or geographic areas (by country and region), providing a more detailed perspective on the impact of emergencies and disasters. For example, by regularly updating DALYs estimates based on the best available data, trends in DRR policies can be monitored over time to assess the impact of macro-level policy interventions. As a result, DALY can be an important tool to support Health EDRM policies aimed at improving the resilience of the general population and particular population groups and reducing disparity in damage.

## 2.3.5 GBD 2017 reporting: a snapshot

The Global Burden of Disease (GBD), which has been affiliated with WHO and the World Bank and is now housed in the Institute for Health Metrics and Evaluation (IHME) at the University of Washington in the USA, is produced by a global network of more than 3600 collaborators from universities, research institutes and government units. Most of these are in low- and middle-income countries *(19)*. Using published studies and available data worldwide, the most recent study as of 2019 *(18)*, GBD 2017, covered 195 countries and territories, with subnational assessments for 16 countries (Brazil, China, Federal Democratic Republic of Ethiopia, India, Islamic Republic of Iran, Japan, Kenya, United Mexican States, New Zealand, Norway, the Russian Federation, South Africa, Sweden, United Kingdom and USA), and calculated DALYs and other health metrics for each year from 1990 until 2017. Data are disaggregated by age, gender, location and year. The study assessed 359 diseases and injuries, and 84 risk factors or combinations of risks *(20)*.

Table 2.3.1 shows seven hazards addressed in GBD 2017. The grouping of diseases and injuries used by the GBD is based on the International Statistical Classification of Diseases and Related Health Problems (ICD-10).

**Table 2.3.1 Hazards currently covered in the GBD projects**

| WHO classification of hazards | GBD cause group | ICD10 codes mapped to GBD causes |
|---|---|---|
| Natural | Exposure to forces of nature | X33-X38 |
| Natural | Environmental heat and cold exposure | L55-L55.9, L56.3, L56.8-L56.9, L58-L58.9, W88-W99, X30-X32, X39 |
| Human-induced | Fire, heat, and hot substances | X00-X06, X08-X19 |
| Human-induced | Exposure to mechanical forces | W20-W38, W40-W43, W45-W46, W49-W52 |
| Human-induced | Interpersonal violence | X85-Y08, Y87 |
| Human-induced | Conflict and terrorism | Y36-Y36.9, Y89.1 |
| Human-induced | Executions and police conflict | Y35-Y35.9, Y89.0 |

The GBD synthesizes a large number of data sources to estimate burden of diseases. Country vital registration data are the primary data source for mortality due to these hazards. The Centre for Research on the Epidemiology of Disasters' International Disaster Database (EM-DAT) (see also Chapter 2.1) served as the GBD's primary non-vital registration source of mortality data due to exposure to forces of nature, and to fire, heat, and hot substances *(21)*. Data sources for conflict and terrorism include the Uppsala Conflict Data Program (UCDP) *(22)*, International Institute for Strategic Studies *(23)*, Robert S. Strauss Center for International Security and Law *(24)*, the Global Terrorism Database (GTD) *(25)*, and the RAND Database of Worldwide Terrorism Incidents *(26)*. Other data sources can be explored via the Institute for Health Metrics and Evaluation's GBD 2017 Data Input Sources Tool *(27)*.

The case studies below illustrate how the burden of disease concept can be interpreted and used for Health EDRM, using data from the GBD 2017. The data in Case Study 2.3.1 can be compared with that for another case of a major natural disaster in Japan, the Great Hanshin Earthquake in Kobe (magnitude 7.3), in January 1995. This shows a similar picture. The earthquake killed 6434 people, of whom 99.5% were residents of Hyogo Prefecture. Many structures were irreparably damaged by the earthquake, including nearly 400 000 buildings *(30)*. The most frequent cause of death was asphyxia due to direct compression of the chest or from being buried under the debris of houses *(30)*. The second most frequent cause of death was severe crush injury.

Figure 2.3.2 shows the age-specific mortality rate (per 100 000) due to natural disasters in 1995 in Hyogo Prefecture. As with the 2011 data for Miyagi Prefecture, the highest mortality rate was observed in the older population at the age of 90–94 years, at 487 (95% uncertainty intervals: 319 to 711) per 100 000 people, 5 to 10 times higher than among those aged under 50 years. However, as with the tsunami in Miyagi, when the burden of the earthquake was measured as a DALYs rate, the burden was highest among both the older population and young children.

These findings imply that, although mortality captures the likelihood (or risk) of dying due to a particular cause, DALYs capture the magnitude of health losses caused by a particular cause. Using a metric of DALYs in measuring the health impact of a disaster, it is clear that young children are more prominently affected. This is in part due to the fact that the burden of a disaster disproportionately affects younger populations, who lose greater healthy lifetime than the older population.

### Case Study 2.3.1
### DALYs produce a different picture of health impact of a disaster

The devastating magnitude 9.0 Great East Japan Earthquake that struck north-eastern Japan on 11 March 2011 and the subsequent tsunami killed more than 16 000 people. There was no major structural damage due to the earthquake itself. In Miyagi, the earthquake is said to have been directly responsible for the deaths of at least four people, but the largest number of tsunami deaths were recorded in this coastal prefecture, accounting for about 60% of total deaths. The nature of a tsunami is such that it usually causes fewer non-fatal injuries than an earthquake, but, rather, is a matter of life-or-death for those who live on the coastline in its path.

Many previous studies indicate that the older population are more likely to die or suffer serious injuries when involved in hazardous events *(28)*. The 2011 disaster in Japan is no exception. Figure 2.3.1 shows the age-specific mortality rate (per 100 000) due to ‘exposure to forces of nature’ (that is, natural disasters) in 2011 in Miyagi Prefecture. The highest mortality rate was observed in the age group over 90 years of age, at 1913 (95% uncertainty intervals 1249 to 2840) per 100 000 people. This is 5 to 10 times higher than among those aged under 50 years. DALYs produce a different picture of the burden of the natural disaster than that the mortality rates: in terms of DALYs rate, the highest burden of the natural disaster was observed in children under five years of age, followed by older age groups (Figure 2.3.1).

**Figure 2.3.1 Age-specific mortality and DALYs rate per 100 000 people due to natural disaster in Miyagi Prefecture in 2011 (Source: *(27)*)**

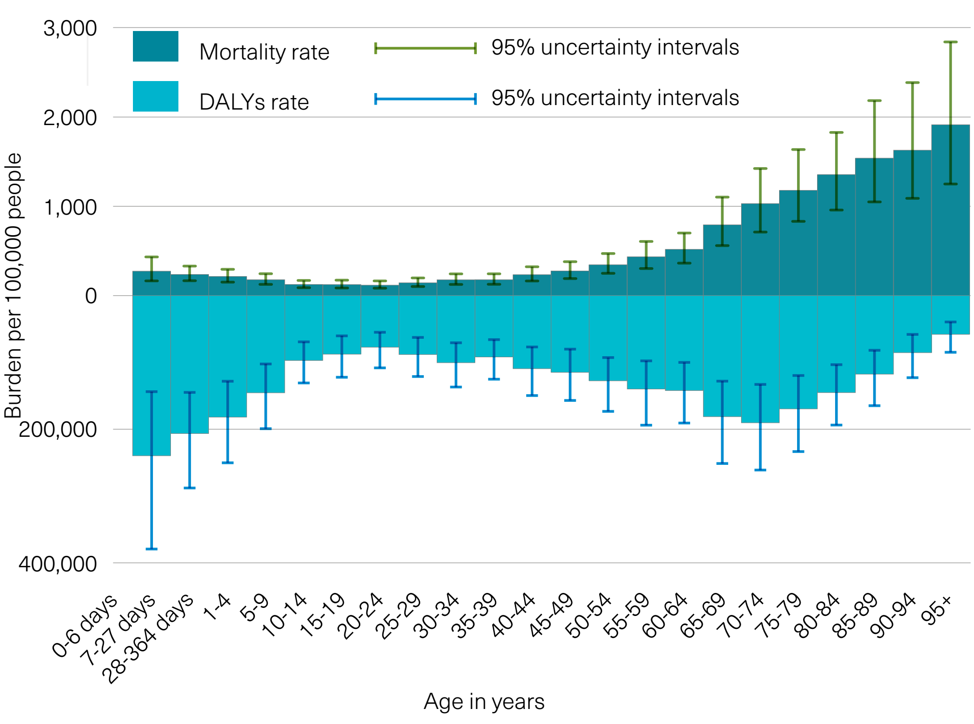
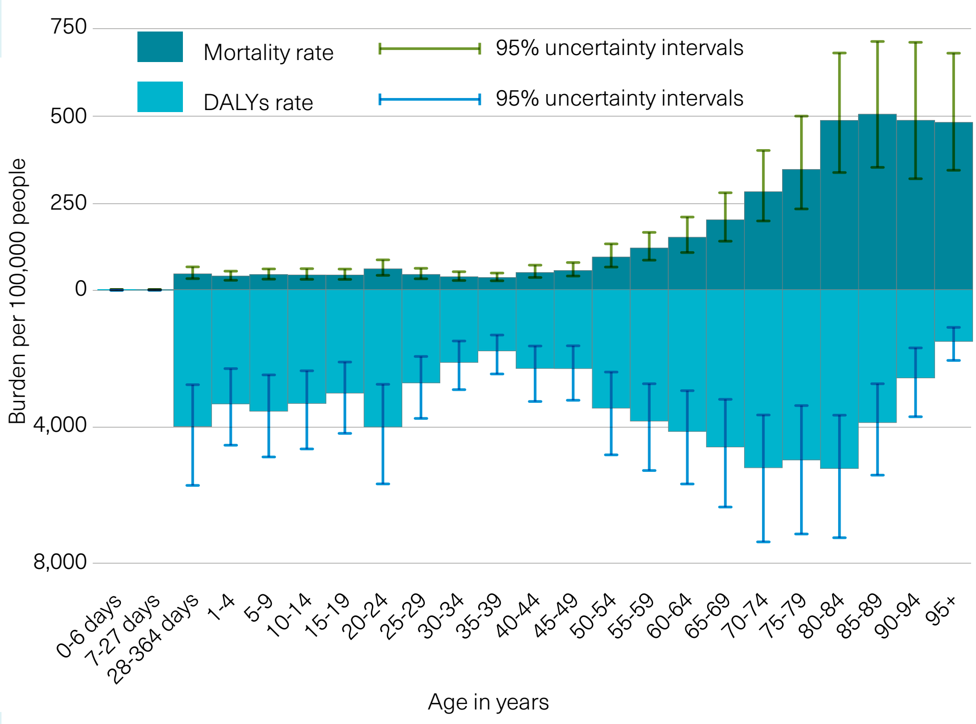


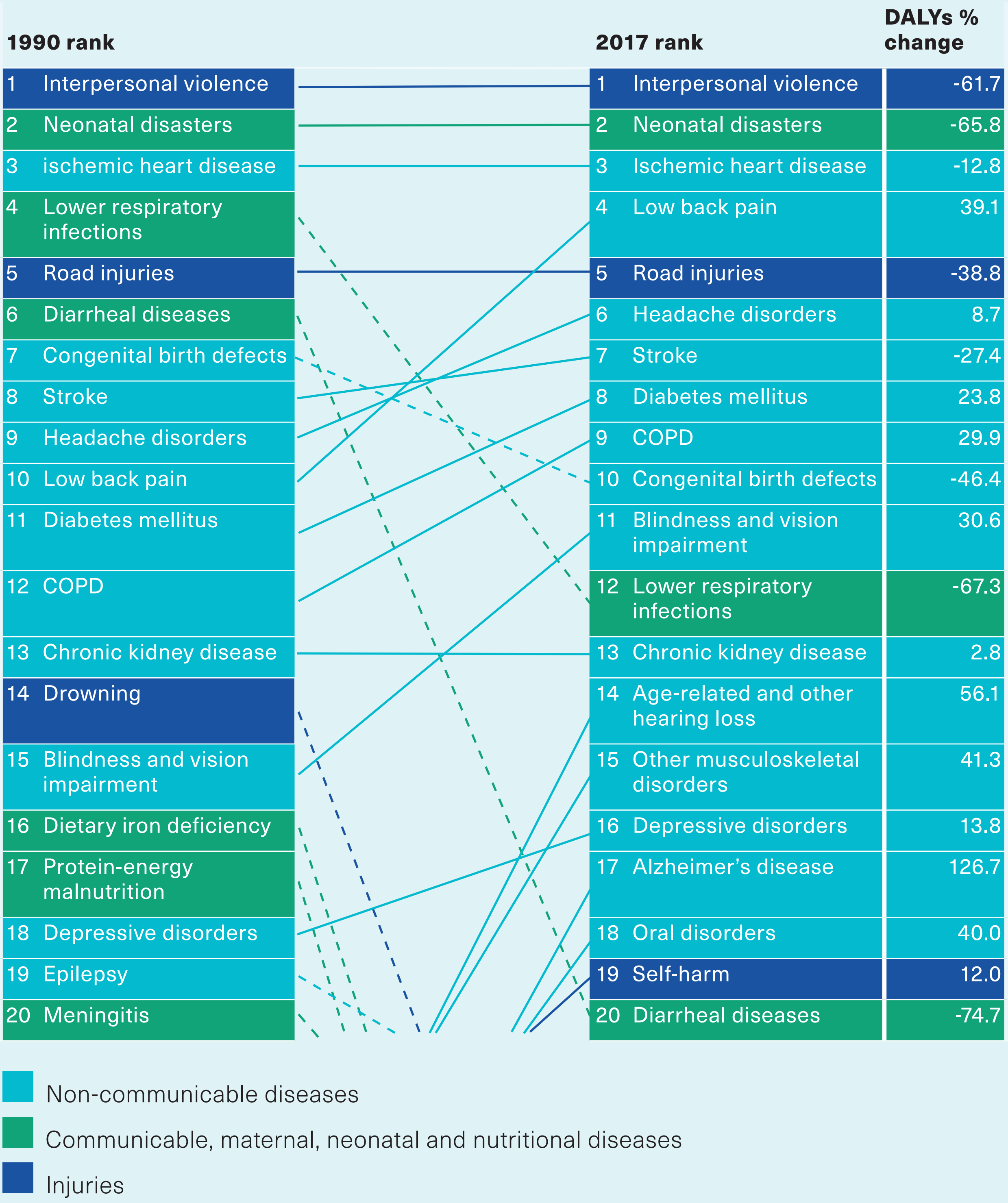
**Figure 2.3.2 Age-specific mortality and DALYs rate per 100 000 people due to natural disaster in Hyogo Prefecture in 1995 (Source: *(27)*)**



### Case Study 2.3.2
### Political violence has persisted in the Republic of Colombia despite several peace processes

In Colombia, the top three causes of DALYs in 2017 were interpersonal violence, neonatal disorders and ischemic heart disease (Figure 2.3.3). These rankings have not changed since 1990, although DALYs due to these causes have decreased by 61.7%, 65.8%, and 12.3%, respectively.

**Figure 2.3.3 Ranking of DALYs in Colombia in 1990 and 2017 for both sexes combined, all ages *(27)***



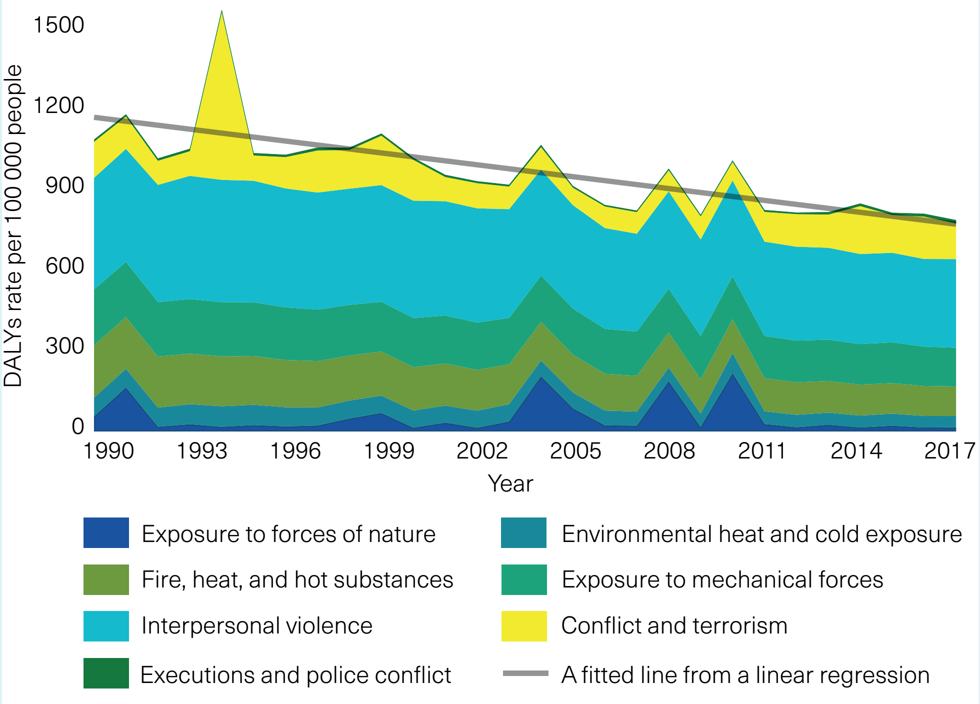
Interpersonal violence, the leading cause of DALYs in 2017, is mainly attributed to homicides related to drug trafficking, illegal firearms and alcohol. The violence primarily affects the younger population, which leads to higher numbers of YLLs and YLDs. Young males in particular suffer from a high mortality rate due to interpersonal violence. It is worth noting that, although rates in Colombia remain high, from 1990 to 2017 DALYs declined by 61.7%, in part due to militaristic and social economic policies aimed at ending armed conflict and eradicating drug trafficking *(31)* which resulted, in 2016, in the end of a 53 year-long civil war through a peace agreement between the Colombian Government and the Revolutionary Armed Forces of Colombia (FARC). Other notable initiatives include banning of carry permits for guns, which started out as a time and occasion specific ban in major cities in the early 1990s, and a general ban in the capital, Bogotá, in 2012 and became nationwide in 2015 *(32-34)*. Furthermore, given the complexity of the relationship between police, crime and communities in Columbia, addressing interpersonal violence through means such as alcohol regulation, which was associated with a lower risk of homicide in the city of Cali, may be an effective intervention *(35)*.

Research points to violence repeating itself, in that children who experience abuse or violence as they grow up are prone to demonstrating and solving conflict with violence as adults *(36)*. In order to halt this cycle of violence, the mayor of Cali, Rodrigo Guerrero, who is a public health expert, stressed the need for Colombia to pursue a profound cultural change, beginning from the very earliest stages of life, so that violence ceases to be a culturally accepted way of resolving conflicts.

### Case Study 2.3.3
### Global DALYs due to the seven hazards are declining

Figure 2.3.4 shows stacked cumulative age-standardized DALY rates per 100 000 people globally due to the seven hazards defined in Table 2.3.1. Among these seven hazards considered in GBD 2017, interpersonal violence has been the main cause of DALYs in recent decades (41.0% on average between 1990 and 2017), followed by exposure to mechanical forces (18.3%); fire, heat, and hot substances (15.4%); conflict and terrorism (13.1%); environmental heat and cold exposure (6.2%); exposure to forces of nature (5.1%); and executions and police conflict (0.8%).

**Figure 2.3.4 Trends in age-standardized DALYs rate per 100 000 people due to exposure to the seven hazards in Table 2.3.1 (Source: *(27)*)**



The grey line on Figure 2.3.4 is an ordinary least squares regression line based on the total age-standardized DALYs rate from 1990 and 2017. This shows a temporal trend in DALYs due to the seven hazards. Between 1990 and 2017, there was a large reduction in the age-standardized DALYs rate, which fell by 34%. The peaks on the figure represent shock events: the 1991 Bangladesh cyclone (exposure to forces of nature), the 1994 Rwandan genocide (conflict and terrorism), the 2004 Indian Ocean earthquake and tsunami (exposure to forces of nature), the 2008 Cyclone Nargis in the Republic of the Union of Myanmar (exposure to forces of nature), and the 2010 Haiti Earthquake (exposure to forces of nature).

## 2.3.6 Conclusions

Disasters and other health emergencies cause substantial mortality and disability. Reliable evidence on the scale of this mortality and disability and how different populations groups are affected is vital to policy planning and the prioritization of interventions in Health EDRM. Using the burden of disease concept helps to provide the comprehensive and comparable data necessary for this. The burden of disease concept is globally recognized as a methodological framework to quantify and compare population health, using the DALY as a summary measure of both mortality and disability. When used in Health EDRM, burden of disease and DALYs allow policy makers and researchers to compare and contrast the health impacts of different events across countries and regions, and over time. This provides them with a foundation for the assessment of programmes and policies and for the planning and analysis of research.

## 2.3.7 Key messages

- **A key foundation for prioritizing policy planning and interventions in Health EDRM is comprehensive and comparable evidence on mortality and disability.**
- **A burden of disease approach quantifies and compares health loss due to mortality and disability for different diseases and injuries.**
- **DALY is a summary measure of population health that integrates mortality and disability.**
- **DALY allows comparisons between different health hazards and offers the ability to assess the impact of DRR strategies.**

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# 2.4

# Databases and registers as tools for disaster epidemiology

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## 2.4.1 Learning objectives

To understand the three major types of databases and registers available to disaster epidemiology researchers, and their associated strengths and weaknesses by:

1. Characterizing the salient differentiating features of these database and register types.
2. Providing case studies and examples to illustrate these and their usage.
3. Highlighting the strengths and weaknesses of each, and providing a global overview.

## 2.4.2 Introduction

The *exposome* is defined as "the totality of human environmental exposures", in other words, all the non-genetic exposures which shape individuals' life-course trajectories *(1)*. Quantification of this all-encompassing concept is challenging at a single point in time, and is even more complex over time – particularly in the context of health emergency and disaster risk management (Health EDRM) when people may be exposed to the risks or consequences of emergencies and disasters. An individual's exposure begins before birth and includes insults from multiple sources. In the normal course of events, genetics has been found to account for only about 10% of diseases, while the remaining causes appear to be from life histories and environment *(1)*. Significant insults from emergencies and disasters have even a greater impact.

A key factor in describing and understanding the exposome and a person's resultant life-course trajectory is the ability to accurately measure germane factors and exposures, and their effects. Databases and registers – due to their rapid evolution, availability, and the ability for them to be linked to other information sources – are increasingly being used by researchers to improve this understanding. Building on the discussion of disaster epidemiology in Chapter 2.1, this chapter outlines three major types of databases and registers that are useful for epidemiological investigations in the disaster context:

- Ongoing population-based databases and registers (typically comprising routinely collected administrative data);
- Pre-existing subpopulation databases and registers (often available from ongoing cohort studies initiated prior to the emergency or disaster event); and
- Post-disaster databases and registers (studies and databases initiated and established after the event and therefore containing no (or little) pre-event information).

### 2.4.3 Ongoing population-based databases and registers

Today's world is increasingly digitized with a vast amount of data produced daily. In 2018, it was estimated that 2.5 quintillion bytes of data were created each day, and this is rapidly accelerating *(2)*. Some 90% of the world's data were generated in the last two years alone *(2)*. Data are being routinely and more frequently collected from increasingly varied sources and archived. The promise of Big Data and machine learning and data science, then, is to map the exposome, and ascertain the contribution of events and exposures. However, much work remains to be done – although initiatives such as New Zealand's Integrated Data Infrastructure (IDI) *(3)* are helping. The IDI is a large national research database holding microdata about all New Zealand people and households. It links detailed data from health, education, justice, income and work, population and many other sources over time. Such databases can provide a holistic detailed baseline account and history of individuals in an emergency- and disaster-affected region, and the resultant effects on those who stay or flee, included on those who were unaffected. Because these data are prospectively collected and provide complete population coverage, they are likely to provide robust and less biased epidemiological estimates of factors and exposures before, during and after an emergency or disaster. However, they are limited by the scope and quality of the data that are actually collected *(4)* and administrative data typically lack important qualitative information. This is because administrative data collected by government agencies are generally for the purposes of registration, transaction, monitoring and record keeping, rather than for research or research-related objectives *(5)*. How these types might be used in Health EDRM research is discussed in Chapter 4.4.

Such broad-based, comprehensive, linked population-based datasets remain uncommon internationally, although this is changing rapidly. For example, in Republic of Estonia, an efficient, secure and transparent nationwide digit ecosystem has been built that includes integrated data from different healthcare providers to create a common record for every patient (https://e-estonia.com). Within the domain of health, medical databases are often massive repositories of routinely collected detailed information and may serve as a robust research tool *(6)*. For example, patient registries with complete nationwide coverage and individual-level linkage potential have existed in the Republic of Finland since 1969, Denmark since 1978, Sweden since 1987, the Republic of Iceland since 1999 and Norway since 2008 *(7)*. These health registers can be used to provide baseline information and to track the impact of emergencies or disasters. Case Study 2.4.1 provides one example in which routinely collected information from Christchurch Hospital in New Zealand is used to assess the impact of the 2010-2011 Christchurch earthquakes and a change in their healthcare service delivery model.

However, routine databases and registers are often not appropriately designed for specific disaster research purposes or do not lend themselves to this. At times, they absorb considerable resources for very little scientific gains *(4)*. Furthermore, the precise exposures or confounders that researchers wish to explore or account for are frequently absent from these databases *(10)*. This, in part, motivated the development of the REporting of studies Conducted using Observational Routinely collected health Data (RECORD) statement to aid transparency and improve research reporting (www.record-statement.org). Although, for hazards that have slow onset but long duration, such as deforestation and air pollution, the ongoing population-based databases designed with long term broad-based measures may be advantageous over post-disaster tailored databases.

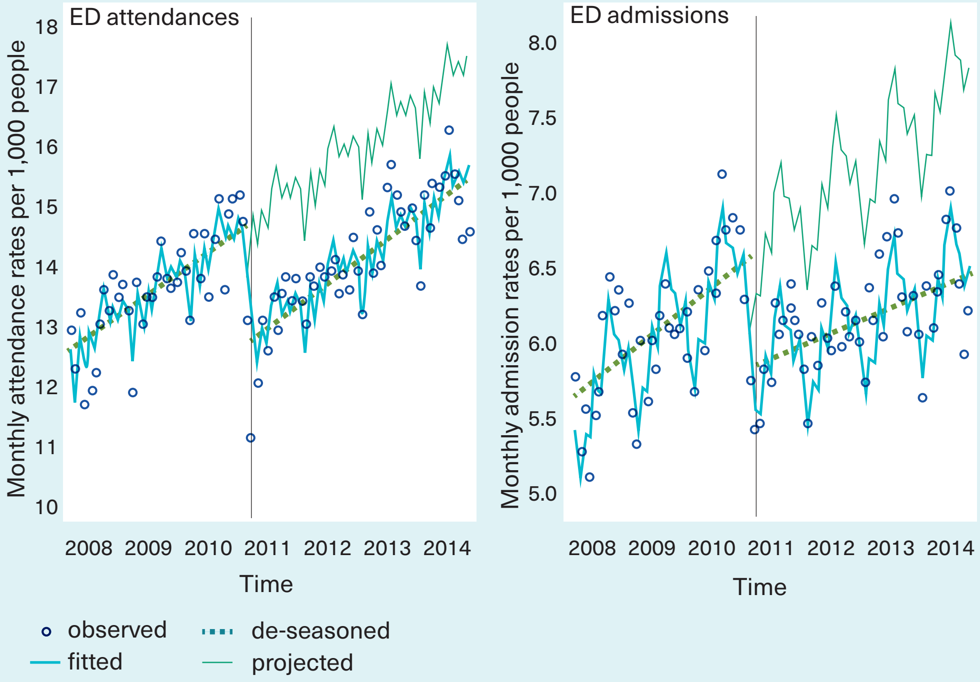
### Case Study 2.4.1
### Measuring the impact of integrated health system changes on emergency department attendances and acute admission, precipitated by an earthquake *(8)*

Hospital systems routinely collect data on a number of activities, including emergency department (ED) attendances and acute admissions. These attendances and admissions are costly and often preventable. Moreover, in many countries, the healthcare service provision is increasingly recognized as being unsustainable. In response, the Canterbury District Health Board initiated a shift to an integrated person-centred healthcare model *(9)*. However, the 2010–2011 Christchurch earthquakes and aftershock series (the most devastating of which occurred on 22 February 2011, resulting in 185 deaths, more than 6500 injuries, an estimated 10 600 people relocating to outside of Christchurch, and costing NZ$ 40 billion – or 19% of New Zealand's Gross Domestic Product) compromised infrastructure and disrupted services, so that this new healthcare delivery model was rapidly implemented. While conceptually appealing, the evidence base for such a service model is relatively weak, and the empirical impact it had within the Canterbury District Health Board was unknown. By interrogating the routinely collected ED attendance and admission records for Christchurch Hospital, the single tertiary hospital in the region serving approximately 500 000 people, one important component of the earthquake impact and change in service delivery model could be measured.

Figure 2.4.1 presents the observed, fitted, de-seasoned and projected standardized population emergency department attendance and acute admission rates, derived from models using Bayesian change-point methods. The 'projected' line gives the predicted rates based on pre-earthquake and pre-existing healthcare delivery model, while the 'fitted' line gives the actual rates derived from the routinely collected data. The demonstrative change post-earthquake, together with the significantly decreased rate of growth in emergency department admissions is also depicted. These findings support the conclusion that, after the earthquake, the Canterbury District Health Board's integrated health systems transformations have resulted in a dramatic and sustained reduction in emergency department attendances and acute hospital admissions.

Figure 2.4.1 shows scatter plots of observed Canterbury District Health Board standardized monthly Emergency Department (ED) attendance rates (left) and Emergency Department admissions (right) per 1000 people (hollow circles), together with a superimposed fitted lined from the full time-series model (solid line), the estimated de-seasoned trend line (heavy dashed straight line) and the extrapolated projected line (grey line). The vertical line denotes the 22 February 2011 earthquake.

**Figure 2.4.1 Scatter plots of observed Canterbury District Health Board standardized monthly Emergency Department attendance and admission rates per 1000 people.**



## 2.4.4 Pre-existing sub-population databases and registers

Another rich source of exposome data arises from serendipitous pre-existing cohort or longitudinal studies that were already being conducted in an area affected by an emergency or disaster. These studies often contain pre-event information from multiple health, social and environmental domains; invariably using instruments with excellent research-orientated psychometric properties. Moreover, participants in these studies commonly have their data augmented by information collected from other sources. This reduces responder burden, and also harnesses a greater information landscape. One such example is the Avon Longitudinal Study of Children and Parents, which was established to understand how genetic and environmental characteristics influence health and development in parents and children *(11)*. Other examples include the nationally representative Demographic and Health Surveys which are regularly conducted in various African, Asian, European, Oceanian, Latin American and Caribbean countries *(12)*, the China Health and Retirement Longitudinal Study *(13)*, and the Nurses' Health Study in the USA *(14)*.

A similar study exists in Christchurch – the Christchurch Health and Development Study, which follows 1265 children born in 1977. At the time of the 2010-2011 Christchurch earthquakes, the Christchurch Health Development Study cohort participants were aged 34 years, with just over 50% exposed to the earthquakes and the remainder unexposed (forming a non-randomized control group). The comprehensive pre-event data, combined with the different earthquake exposure levels, provides a powerful mechanism to understand the disaster impact: the study presented as Case Study 2.4.2, for example, explored the role of peri-traumatic stress in predicting major depression symptoms. Pre-existing longitudinal studies with data linkage capabilities to population-based registers can also provide new possibilities for analysing peri- and post-traumatic stress symptoms following a disaster. For example, when combined with health service use data, a more comprehensive view of the impact of physical and mental trauma on individuals across a longer time span can be gained.

### Case Study 2.4.2
### Understanding the role of peri-traumatic stress and disruption distress in predicting symptoms of major depression following exposure to a natural disaster (15)

Few studies have examined the contribution of specific disaster-related experiences to symptoms of depression. This study investigated this among an existing cohort of individuals exposed to the 2010-2011 Christchurch earthquakes and associated major aftershocks. One of the perennial challenges associated with disaster epidemiology research is the availability of detailed pre-event data. However, Christchurch is home to the long-running Christchurch Health and Development Study, a birth cohort of 1265 children born in 1977. This cohort has now been studied repeatedly from birth to age 35 years, has maintained high retention (79% of those surviving) and the resultant database contains a large repertoire of life-course information. More than 50% of the study cohort were exposed to the earthquakes, and at age 35 years, those exposed were interviewed about their experiences of these earthquakes.

The strengths of this study include the availability of data from a well-studied cohort and the use of a model which tests for both peri-traumatic and post-event distress simultaneously. Pre-earthquake covariates included cognitive ability, prior history of mental disorder and familial socioeconomic status measures. Previous studies which report that major depression is related to post-event factors have not looked at confounders of this association. The study found that peri-traumatic stress is an under-recognized predictor of major depressive disorder following a disaster caused by natural hazards.

### 2.4.5 Post-disaster databases and registers

Pre-existing population-based databases and registers or research-based studies are often inadequate or insufficient to understand the health impacts and service gaps on a population following an emergency or disaster. In such instances, post-disaster databases or registers are needed. These are flexible and tailored to contain instruments and tools that are most pertinent to the specific population and situation. However, critical gaps in observational research instruments still exist, such as the monitoring of long-term mental health or psychosocial risk of people in both a clinical and community setting *(16)*. Moreover, the clear disadvantage of this approach is that predisaster information must be recalled or retrieved retrospectively, which can suffer from important biases, such as selection bias and information bias. Practical and ethical considerations are also paramount. These include interference with emergency responses or recovery, participant safety and sensitivity and ensuring that truly informed consent can be obtained (see also Chapter 3.4). Nonetheless, this is a common and important approach taken by researchers and agencies alike. Examples include the World Trade Center Health Registry *(17)* described in Case Study 2.4.3, the 1995 Oklahoma City Bombing Injuries Database *(18–20)* and the Canterbury Earthquake Recovery Authority Wellbeing Survey *(21)*.

**Case Study 2.4.3**

**World Trade Center Health Registry (17) and the longitudinal determinants of depression among World Trade Center Health Registry enrollees, 14 to 15 years after the 9/11 attacks *(22)***

The World Trade Center Health Registry is now the largest registry in UnS' history to track the health effects of a disaster. It tracks the impact of the 9/11 attacks, a series of four coordinated attacks by the terrorist group al-Qaeda on 11 September 2001. The attacks killed 2996 people, injured more than 6000 others, and caused at least US$ 10 billion in infrastructure and property damage, with other dying of 9/11-related cancer and respiratory diseases in the months and years after the attacks. The World Trade Center Health Registry was established post-disaster, and enrolment was voluntary for people who lived, worked or went to school in the area of the disaster, or who were involved in rescue and recovery efforts. To enrol, participants completed a confidential "Wave 1" health survey in 2003 or 2004. More than 71 000 people enrolled, including 4000 survivors of the collapsed World Trade Center towers. Multiple measurement waves have followed, with surveys in 2007, 2011 and 2015. The results of these surveys help determine the extent to which physical and mental health conditions have persisted, and whether any new symptoms and conditions have emerged.

Another important goal is to identify and help address gaps in physical and mental health treatment. For example, in Jacobson and colleagues (2018) study, the longitudinal determinants of depression among different PTSD levels were examined for 21 258 enrollees who had completed four questionnaires over 14 years of follow-up. They found that 18.6% experienced depression, and it was more common among those who had ever experienced PTSD (56.1%) compared with those who had not (5.6%). These findings highlight the substantial burden of depression in a trauma-exposed population 14 to 15 years after the disaster, especially among those with PTSD. Many World Trade Center Health Registry research outputs have been published *(23)*. Moreover, like many bodies (such as the Integrated Data Infrastructure in New Zealand), the World Trade Center Health Registry welcomes proposals for new studies from external researchers. Upon approval, researchers can request de-identified survey data or request that the Registry facilitate recruitment of enrollees into a study.

## 2.4.6 Conclusions

Disaster epidemiology researchers are able to use a variety of health-related databases and registers when studying topics of relevance to Health EDRM. A broad overview of the important strengths and weakness typically associated with databases and registers is presented in Table 2.4.1. However, each specific dataset and scenario may have other important strengths and weaknesses and requires careful critique and evaluation before it is used in research.

### Table 2.4.1 Important strengths and weakness typically associated with databases and registers used as tools for disaster epidemiology

| Major register types | |
|---|---|
| **Strengths** | **Weaknesses** |
| **Ongoing population-based databases and registers:** | |
| Cost: usually relatively inexpensive;<br>Coverage: usually population wide;<br>Predisaster information available;<br>Time: relatively quick to undertake. | Not designed for disaster research;<br>Important instruments or variables may be missing or have poor psychometric properties;<br>Database linking may be difficult or impossible;<br>Selection bias may mean that those missing from the register are importantly different from those included;<br>Data are often aggregated or grouped in ways that lead to findings suffering from the ecological fallacy;<br>Big Data datasets require data storage systems, computation capacity and performance, and analytical techniques that are (currently) often beyond the scope of many individual researchers. |
| **Pre-existing sub-population databases and registers:** | |
| Cost: potentially inexpensive if 'added-on' to an existing study;<br>Predisaster information available<br>Typically cover subject matter in-depth;<br>Capability to augment with qualitative information;<br>Instruments normally designed for research purposes and often tested for psychometric properties and reliability. | Not originally designed for disaster research, so may miss important factors or exposures;<br>Recruitment or retention to the existing study may limit the external validity of finding;<br>Study participant sample size may lack statistical power. |
| **Post-disaster database and registers:** | |
| Designed and tailored for disaster and population of interest. | Cost: usually expensive;<br>Predisaster information is limited;<br>Potentially time consuming and resource or expertise intensive;<br>Timely collection of data may be unethical;<br>If a multi-agency, multi-sector research collaboration then competing interests may exist and hamper the scope. |

## 2.4.7 Key messages

- **There are multiple and growing sources of data available for disaster epidemiology research. Knowledge of the exposome can be extended and developed by using and linking these data, and exploring how emergencies and disasters affect people's likelihood of mortality, morbidity and life-course trajectories.**
- **The expediency of using routinely collected data is often offset by the coverage, depth and quality of the variables available to researchers. This often requires initiation of a post-disaster study, that is both specifically and contextually relevant to the disaster and the population affected.**
- **As more better quality and richer data are collected, Big Data, machine learning and data science are likely to play an increasingly important role in disaster epidemiology research. However, possible avenues to augment these quantitative data with qualitative information still need to be explored.**

## 2.4.8 Further reading

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# 2.5

# Identifying and engaging high-risk groups in disaster research

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## 2.5.1 Learning objectives

To understand how to identify and support high-risk groups in disaster research by:

1. Describing high-risk groups in the community.
2. Addressing barriers to inclusion through strategies for sampling, recruitment and data collection.
3. Engaging co-researchers or community advisors within the population of interest to ensure inclusive, ethically responsible research processes, and valid findings.

## 2.5.2 Introduction

The growing frequency and intensity of disasters will leave more people vulnerable to physical and mental health risks than ever before. The consequences of a changing climate will exacerbate existing inequalities in health and broaden the geographic and social patterns of disparity *(1)*. High-risk groups are defined by disadvantages resulting from the characteristics and intersection of age, gender and sexual identities, race, culture, religion, disability, socio-economic status, geographical location, or migration status. Importantly, it is not only the stand-alone identities, but the intersection of different identities that can create or worsen risk *(2)*. These groups may have a history of marginalization, stigmatization, existing health conditions, or developmental vulnerability that amplifies health risk when intersected with disaster exposure. An individual's disaster vulnerability is dependent on contextual factors and timing, which means their level of resilience may be depleted at times, but strengthened at others (Chapter 3.2). However, several risk factors have been identified that contribute to consistent patterns of disaster risk. It is therefore critical that health services and DRR policies be informed by the growing evidence base to ensure that services cater to the specific needs and capacities of high-risk groups.

Health EDRM strategies seek to prevent and mitigate risks among those most vulnerable in all phases of the disaster cycle (Chapter 3.2). It is important that research protocols are designed to be inclusive of groups that may be high risk and understand their needs across all these phases. The following examples highlight potential research topics that engage high-risk groups across each of the four phases of the cycle:

i) Prevention/mitigation: Identifying specific disaster risk perceptions among low-income migrant and seasonal farmworkers *(3)*.

ii) Preparedness: Assessing preparation for medication access fluctuations or knowledge of accessible evacuation routes among people with chronic disease *(4)*.

iii) Response: Examining psychological perspectives and reactions among adolescents affected by earthquakes *(5-6)*.

iv) Recovery: Determining the processes of restoration and barriers to recovery among persons with disabilities *(7).*

When conducting population-based research, it may be easy to miss the distinct vulnerabilities of high-risk communities hidden by political or social status, or those who are at risk of being marginalized, stigmatized or persecuted if identified. Accordingly, targeted research that is sensitive to the political and social context will provide greater representation and deeper understanding for the circumstances of specific communities.

Groups considered to be high-risk will simultaneously demonstrate specific strengths. Individual resilience, strong family or peer attachments, preparedness knowledge, established connections within the community, and experience of earlier disasters will influence a person's capacity to respond and recover from a disaster. It is vital that disaster research investigates and promotes both the heightened risk and evidence of resilience for high-risk populations. Research will thus play an important role in informing the equitable delivery of services in a context where resources are often severely limited. This chapter presents a concise literature review, with case studies from high-, middle- and low-income countries, to provide guidance in conducting inclusive and ethically responsible research.

## 2.5.3 High-risk populations

The vulnerabilities and resiliencies of populations may shift depending on the disaster scenario (Chapter 3.2), with different disasters distinctively heightening specific risks. For example, in a disaster in which evacuation is necessary, careful planning will be required for those with mobility issues – such as people with physical disabilities that inhibit movement, functionally limited elderly and other homebound persons. Similarly, those who are less well connected to mainstream communication services due to language restrictions, education level, migration status or other means of marginalization, may not receive adequate guidance on disaster risk management or access to health services. In heatwaves, cold-waves, heavy rainfall and flooding events, which require populations to stay indoors, the homeless and those living in compromised housing are at increased vulnerability and may require appropriate shelter. It is important that research defines and addresses issues relevant to high-risk populations to support evidence-informed DRR practices and policies. The following section addresses some common factors that have potential to increase vulnerability.

### 2.5.4 Age and developmental stage

Both young and old age present potential risks in disasters. Children and adolescents (aged 0-19 years) are vulnerable because at early ages they often depend on caregivers to supply their basic needs and support their wellbeing *(8)*. Their age-specific needs, such as an uninterrupted supply of infant formula, identification of safe routes to school or distribution of developmentally appropriate disaster preparedness information, may be easily overlooked in disaster risk management activities *(9)*. During later adolescence, the dependence on parents will diminish but family support often remains a critical protective factor following trauma *(10)*. Adolescent girls in particular begin to have reproductive health needs that should be supported through comprehensive education and services.

Short and long-term separation from parents during a disaster is a particularly important stressor for children. Short-term separation may occur if a disaster strikes while children are at school or home alone, whereas long-term separation results from displacement or the death of parents *(9)*. Without caregivers, children are at increased risk of abuse, neglect or trafficking *(11)*. Although many children and adolescents report considerable resilience and post-traumatic growth after emergencies; high levels of disaster exposure, loss of resources, security risks, and separation play a significant role in the potential development of psychological and physical trauma *(10, 13)*. Case Study 2.5.1 provides further detail on adolescents' needs and engagement in DRR strategies in China and Nepal.

#### Case Study 2.5.1
#### Conducting mixed methods disaster research on adolescent engagement in DRR in China and Nepal

Despite the increasingly active role that young people are taking in DRR and climate action, the specific needs and roles of adolescents are often overlooked. The collaborative Study on Adolescent Resilience after Disasters was conducted in Nepal and south-western China to understand adolescents' disaster-related risks, mental health needs, and engagement in DRR *(10)*. Key partnerships with local organizations were established to inform the development of the study, support access to the target population, lead data collection, and guide the interpretation of results and dissemination of findings. In addition to the participation of adolescents aged 13 to 19 years affected by disasters, the study included a wide range of stakeholders involved in adolescent development such as parents, teachers, healthcare professionals and community leaders.

Using a mixed methods design (see Chapter 4.13), the study comprised an in-depth qualitative study of risks, strengths and opportunities for adolescents affected by disasters, followed by a large-scale quantitative assessment. For the qualitative study, purposive and snowball sampling were used to recruit the target population, ensuring access to participants beyond the researchers' networks. Informed consent was sought for all participants and from caregivers for those under 18 years of age.

Semi-structured, in-depth key informant interviews and focus group discussions were conducted with a total sample of 69 adolescents and 72 adults across both countries. Five major themes were identified in the analysis of data on DRR for adolescents: (i) the importance of adolescent safety and security post-disaster; (ii) adolescent participation in disaster preparedness; (iii) disaster response tailored to adolescents' needs; (iv) the need for evidence-based psychosocial support; and (v) acknowledgement of adolescent participation in disaster risk management *(10)*. The qualitative process identified not only the strengths and weaknesses of current practice, but also recommendations voiced by participants, particularly adolescents.

Adolescents had been active participants in the disaster risk reduction process in both China and Nepal. While coping with their own experience of trauma and loss after disasters, many reported involvement in delivering first aid, participating in rescue efforts, promoting preparedness strategies, arranging security surveillance in temporary camps, and caring for family members *(10)*. The study therefore highlights the importance of recognizing co-existing resiliencies and threats for high-risk groups, revealing a need for DRR programming that supports adolescent safety and empowerment after a disaster *(10)*.

Similarly, although not all elderly are at higher risk during disasters, older age does typically come with greater health needs and vulnerabilities. Elderly people (defined as 60 years and above) *(13)* may have deteriorating physical abilities and in some cases, experience difficulty performing activities of daily living (ADL) *(14)*. "Activities of daily living" comprise a person's basic functional ability, including bathing, dressing, eating, getting in and out of beds and chairs, using the bathroom and mobility in the home. Instrumental Activities of Daily Living (IADL) comprise the ability to live independently within a community, including capacity to prepare meals, manage money, shop, use the telephone, take prescribed medicines correctly, complete light housework and travel outside. Older persons may also have diminished sensory capacities or ability to regulate body temperature and pre-existing medical conditions, such as dementia and mental health conditions *(14–15)*. These impairments may present as vulnerabilities in disasters, requiring the provision of additional functional assistance and care.

### 2.5.5 Gender and sexual identities

Women, girls and people with non-binary gender can be disproportionately affected by disasters, because of societal barriers, restrictions on freedom of movement or access to prevention, response and recovery services, specific health needs and higher risk of domestic and sexual violence *(16)*. Depending on the cultural context, women and girls may hold a lower social status in the community and have reduced access to resources such as education, income or health services *(8, 17)*. Furthermore, their capacity to take desired preventative actions in disasters may be hindered by unequal power dynamics and differing risk perceptions between genders *(18–19)*. They may have roles of caretaking and responsibilities that reduce their mobility and increase their workload *(8)*. There are also specific health and resource needs of women who are pregnant, menstruating or lactating *(21)*. Pregnant women may have reduced mobility, heightened nutritional needs, and require prompt access to healthcare services. Menstruating and lactating women require regular access to private settings and provision of menstrual hygiene resources.

In post-disaster settings, women have a higher risk of experiencing sexual abuse and domestic violence *(21–22)*. In a study of 82 cases of violence against women and children following the 2011 Great East Japan Disaster, Yoshihama and colleagues *(23)* found that domestic violence increased in severity in the year following the disaster. Similarly, non-partner violence occurred when perpetrators were able to exploit the victims' financial or social vulnerability, particularly in insecure settings such as evacuation centres or temporary housing *(23)*. These findings are consistent with reports of exacerbated domestic and sexual violence following Hurricane Katrina *(22)*, Australian bushfires *(21)*, and the Indian Ocean tsunami *(18)*.

In many settings, members of the Lesbian, Gay, Bisexual, Transgender, Queer, and Intersex (LGBTQI) communities are at risk of experiencing stigma and discrimination both before a disaster and during the response and recovery periods, heightening their disaster vulnerability and restricting access to health-related services. For example, in evaluations of prior disaster response programmes, same sex couples and people with non-binary gender have experienced exclusion from shelter and aid due to policies that use traditional definitions of family *(24)* or gender *(25)*. Furthermore, members of the LGBTQI community may fear violence or discrimination should their identity be revealed as a result of accessing health services *(26– 27)*. It is important that Health EDRM researchers consider the broad spectrum of gender and sexuality, and how existing policies may impact the development of assessment protocols, interventions and systems of evaluation. For example, training packages recently developed by the International Organization of Migration (IOM) were designed to support effective assistance for LGBTQI people in humanitarian emergencies and have relevance for the development of inclusive research protocols *(28)*.

### 2.5.6 Pre-existing chronic conditions

Pre-existing chronic conditions can be exacerbated by disaster-related disruptions to medication supply, routine health care and critical infrastructure. Survivors of heart disease and stroke, or people with hypertension and diabetes require regular access to medications *(29)*. Disrupted treatments for those with cancer or chronic kidney disease could affect their health, and cause patients to have weakened immune systems and be at higher risk of infections and injury *(30)*. Home-based treatments could be affected by loss of electricity, such as oxygen therapies for patients with severe respiratory diseases *(30)*. Furthermore, those with pre-existing psychological difficulties are at risk of poorer mental health outcomes after a disaster *(31–32)*. Case Study 2.5.2 demonstrates the impacts of disrupted treatments for people with chronic disease.

### Case Study 2.5.2
### Assessing the impact of Hurricane Katrina on persons with chronic disease *(33)*

Hurricane Katrina, a category 4 storm, landed in the south-eastern USA in August 2005 causing more than 1600 deaths and the displacement of 1.3 million people *(34, 35)*. While chronic disease patients are known to suffer disproportionately in disasters, the extent to which treatments are disrupted is not well known. A study was conducted to assess the causes and extent of chronic disease treatment disruption among hurricane survivors *(33)*. A large population-based sample of English-speaking adults over 18 years of age participated from January to March 2006, five months after the disaster *(33)*. Two sampling frames were used: a telephone bank of households located in counties impacted by the hurricane, as defined by the USA Federal Emergency Management Agency, and cellular and land-based telephone numbers from an application for requesting American Red Cross assistance. These sampling frames were examined and found to be relatively robust, especially since many displaced households forwarded their pre-hurricane numbers to reachable numbers. The sampling strategies included random digit dialing from the telephone lists and oversampling of the New Orleans area, which was severely impacted by the hurricane. A prescreening questionnaire was used to determine eligibility based on pre-hurricane residence, after which 1043 participants were included in the final sample, with a 41.9% response rate *(33)*. Information was gathered on demographics, residence, social network, chronic conditions and treatment. Weights were applied to reduce potential overlap of the two sampling frames and to adjust for differences of the sampling method with the general affected population.

The study revealed that 73.9% of participants reported chronic conditions prior to the hurricane, and among those, 20.8% reported disrupted treatment after the hurricane *(33)*. Treatment disruptions were more common for mental disorders, diabetes and cancer, where the lack of treatment had asymptomatic consequences, rather than chronic conditions that would become symptomatic without regular treatment, such as respiratory, cardiovascular and musculoskeletal conditions *(33)*. Treatment was more likely to be disrupted among those who were under 65 years of age, with fewer close friends and family nearby, and for those who experienced more residential instability after the hurricane. Common reasons for treatment disruption included lack of access to physicians, lack of access to medication, and problems with finance, insurance, transportation or demands on time *(33)*.

The use of a telephone sampling methodology would have excluded those unreachable by telephone and possibly the most disadvantaged or most seriously ill. Furthermore, landline telephone surveys were more likely to recruit older participants, which may account for the high rate of chronic conditions in the sample. Although the study did not comprehensively collect data on all chronic conditions, or include details on disease severity, extent of treatment cutbacks and their clinical outcomes, it highlights the importance of treatment continuity for people with chronic disease affected by disaster.

Overall, recommendations were made to anticipate chronic care needs in disaster management plans and enable continuation of treatment by ensuring timely reestablishment of primary healthcare systems, access to medical records, and activation of portable emergency insurance coverage.

### 2.5.7 Persons with disabilities

Persons with disabilities “include those with long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” *(36)*. This is not a homogeneous group, and their vulnerabilities, which cover a diverse range, are likely be exacerbated differently depending on the hazard. Specific disabilities may include acquired brain injury, blindness, deafness, neurological conditions, spinal cord injury, reduced limb use and amputation which may hinder one’s ability to receive or act on disaster information *(37–38)*. For example, in an UNDRR survey on persons with disabilities, a respondent described that “Because I can’t hear sirens, when there is severe weather, I have to stay awake to watch storms until they are all gone” *(39)*. If an evacuation is required, those with mobility issues within the evacuation parameters would be at increased risk. Persons with disabilities are often overlooked in receiving assistance *(37)*. Compounding factors that increase barriers to assistance include isolation, stigma, inaccessible resources and services, communication difficulties and cognitive impairment *(40)*. Furthermore, people with a disability can be especially vulnerable if they have lost their usual supports during or after the disaster, because they may be deprived of the care that they need *(8)*.

### 2.5.8 Other marginalized groups in the community

Other marginalized groups in the community may include migrants, Indigenous and First Nations peoples, undocumented persons, displaced persons, those living in poverty and the homeless. Marginalization may prevent access to health care, resources, or information *(41)*. In some disaster settings, marginalized groups (such as people living in poverty) may comprise the majority of the population. People at risk of discrimination and inequity may also be more likely to reside in risky living conditions *(42–43)*. For example, despite the high quality health care available in parts of the Eastern Mediterranean region, refugees residing in those countries may be less likely to be able to access health services and obtain pharmaceuticals due to policy, social or economic disadvantage *(44)*. Furthermore, literacy, language, different abilities or cultural differences may prevent people from receiving and understanding disaster warning messages, particularly if the messages are only provided in the dominant language or via mainstream communication channels *(37)*. People living in geographically remote communities may be similarly vulnerable due to poor communication pathways, road access and distance from disaster prevention, preparedness, response or health services.

### 2.5.9 Barriers and strategies in conducting research with high-risk groups

Once high-risk populations have been identified, the research process might encounter challenges in sampling, recruitment and data collection. High-risk groups may overlap with hard-to-reach groups that are difficult for researchers to access. For some, it may be dangerous to self-identify, especially those with illegal status, mistrust in authorities or those susceptible to stigma and discrimination *(45)*. High-risk groups can also be low in numbers within the population or geographically dispersed.

**Sampling**

Sampling can be one of the main barriers to conducting rigorous research with high-risk groups. A regular random sampling method is often inadequate to acquire sufficient sample sizes (that is, statistical power) of those who are hard-to-reach *(45)*. The list of all potential participants in the population of interest, also known as the sampling frame, might be unknown, preventing the use of probability sampling to help ensure that results are representative. Alternative non-probability sampling methods may be used depending on the research study *(45)*. These include convenience sampling, which selects participants that are accessible and eligible for participation. Purposive sampling selects participants that fit a certain inclusion criterion relevant to the study purpose. This may be complemented by 'snowball' sampling or respondent-driven sampling, where participants assist in recruiting more participants from their social networks, enabling an expansion of the sample group beyond the researchers' links. Low prevalence population sub-groups can also be oversampled in order to obtain more data for minorities *(46)*. Other more complex sampling methods include targeted sampling or venue-based time-location sampling, where participants are sampled from an exhaustive list of venues that the target population frequents *(47)*. High-risk groups can be located in places that they commonly attend, such as schools, clinics, community events or certain residential neighbourhoods *(48)*. A combination of sampling strategies can be used to best reach the high-risk group.

Sampling should be conducted in collaboration with community organizations that have access to the target population. Stronger research outcomes can be achieved by partnering with organizations led by members of the high-risk group, or that have direct access to such groups, through service delivery or advocacy *(49)*. It is important to include relevant stakeholders in the research, such as community group members, hospital staff, informal caretakers of patients, and guardians of children, as they may add insight or a different perspective into the circumstances of the target population (see also Chapter 4.12). Community advisory boards also play an important role in guiding the development of research protocols, sampling strategies and the interpretation of findings. Working with partner organizations and community advisory boards can help to build trust, which is critical to the research process and will assist with the following stage of recruitment.

There are limitations and biases that occur with each sampling method, which may affect the research results. Selection bias is introduced by the way individuals are chosen as participants. For example, sampling chronic disease patients at local public hospitals would exclude those who attend private clinics only, or those who do not seek treatment for their conditions. Non-response bias occurs when those who participate in the study are inherently different from those who refuse to participate. This can occur with telephone surveys, mail-surveys, internet sampling, and is of particular concern in follow-up studies. Gatekeeper bias, where participation is limited by those who provide entry into the community groups, may restrict the types of participants that can be involved in the study. Addressing biases through a more comprehensive or open sampling strategy is important to ensure the rigor of the study.

**Recruitment**

Low recruitment rates are often highlighted as a challenge for researchers working with high-risk communities. Lack of trust in the researchers and the fear of being mistreated or exploited are important considerations that may present potential barriers to recruitment *(45)*. For example, a follow-up study on PTSD in the 2 to 3 years after the September 11 terrorist attacks in New York described the limitations of potential self-selection and nonresponse bias, despite having used a large registry and multiple recruitment methods *(50)*.

Such issues could be addressed from the outset by devoting sufficient time and resources to building community relationships. Long-term partnership with the community can in turn foster interest and engagement among potential participants. Trust can be developed by working with and engaging the support of community, religious leaders and local authorities, employing members of the high-risk group as research investigators, staff or translators, and involving community groups in the research process *(45)*. Engagement can be fostered with the use of culturally and linguistically appropriate materials, social marketing strategies such as media and advertisements, and providing reimbursements for participants' time and travel expenses *(45)*. Furthermore, increased sense of ownership can assist recruitment, particularly if the research is community-driven and the results are shared back to the community *(45)*.

The most effective methods of recruitment vary, including personalized outreach and online recruiting. For example, a study in a multi-ethnic neighbourhood in south England found that local advertisements were found to recruit more white participants, while ethnic minorities were recruited more effectively using interpersonal contacts and institutional contacts, respectively *(51)*. A study in the Philippines after Typhoon Haiyan explored both the usefulness and disadvantages of Facebook as a recruitment tool in the general population *(52)*. Social media is an efficient recruitment tool that supports participant independence and geographical diversity, enabling engagement in areas outside the researcher's physical reach. However, online recruitment is self-selecting, vulnerable to noise, and may not be representative of the general population *(52)*. What works in one population group may not work in the next, and so an in-depth understanding of the worldview, preferred communication networks, and interests of the group of interest is critical.

## 2.5.10 Data collection

The methodology used for data collection may differ depending on the study design. Qualitative research, as discussed in Chapter 4.12, may capture greater complexity and enable deeper involvement of high-risk group members. In contrast, quantitative research may enable greater generalizability through measurable data. A combination of quantitative and qualitative methods in a mixed-methods study design, as discussed in Chapter 4.13, may allow for both complexity and greater generalizability. Case Study 2.5.1 illustrates this. Longitudinal research presents opportunities to examine trajectories of change after disasters, and the impact of interventions within communities. Researchers, however, may experience difficulty in retaining participants in longitudinal assessments, especially among more transient populations such as migrants, nomads, and those who are homeless. Thus, flexibility is needed to cater to participants' circumstances. Pilot testing of the research materials is also necessary to ensure that the research questions and measures are relevant and appropriate to the high-risk group.

Participatory action research (PAR) (as discussed in Chapters 3.1 and 5.1), which engages participants as co-researchers, challenges traditional power relationships and knowledge through an emphasis on equity and participation *(53)*. Participatory action research (and complementary approaches such as critical participatory action research and youth participatory action research) provides an opportunity for more targeted and critically valid research that includes groups less often represented in the scientific literature. In studies relevant to DRR and climate change, participatory action research has been used to engage typically marginalised groups and promote important messages of risk and disaster management *(54–55)*. The use of participatory action research in the Torres Strait Islands has promoted the combination of different types of expertise, intergenerational knowledge transfer, and community engagement in climate action and DRR *(56)*. Alongside these approaches, working with a culturally-secure lens such as the adoption of an Aboriginal worldview when working with Indigenous people *(57)*, and decolonising research strategies, will support stronger and more trusting relationships with participants, more reliable measurement, and accurate interpretation of the data.

## 2.5.11 Ethics Approvals and Considerations

Chapters 3.4 and 6.4 discuss key aspects of the ethics of research and obtaining ethics approval. However, when working with high-risk groups it is especially important to be vigilant about possible ethics violations, intended or unintended. A systematic review of published guidelines on research ethics in disaster settings highlighted the importance of obtaining formal approvals, but also addressing issues of vulnerability in research protocols *(58)*. Among the vulnerability factors identified, reducing risks of physical harm, retraumatization, manipulation, exploitation, unrealistic expectations and stigmatization were central to ethical research processes *(58)*. It is important to obtain informed consent from all participants. Consent can be obtained on multiple occasions, including at the end of data collection, and from multiple agencies, such as the community, parent and participant, to empower informed decision making *(59)*. For people with less access to education, language restrictions, severe mental health issues or cognitive difficulties, information about the research purpose and the participant's rights must be presented in a format tailored to promote comprehension *(60)*. Space should be given to participants to refuse the study without pressure or persecution, and to ask questions about the research activities.

It is vital that ethics approval is obtained from the researcher's appropriate ethics committee or institutional review board, as well as ethics boards relevant to the research setting (such as national ethics committees, local institutions, or protective bodies for more vulnerable populations).

## 2.5.12 Conclusions

Health EDRM seeks to prevent and mitigate disaster risks particularly among the most vulnerable in society (Chapter 3.2). Identifying the factors that may elevate a group's risk during or after disasters, and working with the community to create inclusive research protocols will improve the equity of disaster risk management. Consideration of diversity within and between groups is important, as is attention to the role of intersectionality. Health EDRM research has an important role to play in expanding the evidence base on best practice for high-risk groups that are too often neglected in policy and programming. A robust evidence base will support the effective and equitable delivery of disaster prevention, preparedness, response and recovery services in environments that are often severely resource constrained. Research should support decision making to determine *who* is best served by *which* services, and *when (61)*. Consideration of the factors that heighten risk, as well as the unique capabilities and strengths that support resilience is critical. Furthering our understanding of each group's specific disaster risks, resilience, preparedness and responses, will enable the formulation of inclusive and holistic disaster risk management plans, effective leadership, and equitable policies beneficial to health.

## 2.5.13 Key messages

- **Health EDRM research with an inclusive focus on high-risk populations should be conducted across the entire disaster cycle and may vary according to the characteristics of the disaster and community.**
- **Children, elderly, gender and sexual minorities, those with pre-existing chronic conditions or disabilities, ethnic minorities, migrants, displaced persons and other marginalized groups are common high-risk groups to be considered. Intersectionality plays a significant role in capacities and heightened vulnerabilities.**
- **High-risk populations may be difficult to reach, which can affect sampling, recruitment and data collection.**
- **Inclusive and ethically responsible research protocols must consider the impact of research on high-risk populations and guide reliable and thoughtful dissemination of findings.**

## 2.5.14 Further reading

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## 2.6

# The current state of the evidence: Mapping the evidence and systematic reviews

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### 2.6.1 Learning objectives

To understand the importance of the following when considering the current state of the evidence and systematic reviews as a source of information for research in health emergency and disaster risk management (Health EDRM):

1. The essential elements of Health EDRM as they pertain to various stages of the emergency management continuum.
2. The current level of research and available evidence to standardize the application and practice of these essential elements in Health EDRM.
3. The optimal modalities for generating additional evidence for elements currently deemed deficient.
4. The barriers and difficulties in conducting systematic reviews and research during emergencies and disasters.

### 2.6.2 Introduction

The impact of natural hazards in human and economic costs has increased considerably in the past two decades, raising a global alarm. Furthermore, there are concerns about the adverse effects of extreme weather and climate change, which call for an all-hazards approach to emergency and disaster risk management. The United Nations (UN) Secretary-General's Special Representative for Disaster Risk Reduction (DRR), Mami Mizutori, said on 23 July 2018: "Every year disasters cost the global economy an estimated US$ 520 billion, displacing millions of people and pushing many of them into poverty. Reducing economic losses from disasters has the power to transform lives" *(1)*. Health EDRM research has an important role to play in meeting these challenges and concerns.

The public health impact of emergencies and disasters includes direct and indirect mortality and morbidity, trauma, injuries and disability. Health systems are also adversely impacted through damage to health infrastructure *(2)* and over-burdening of health systems in the wake of increasing demand for a variety of health services. Due to the urgent nature of emergencies or disasters, health behaviours and actions surrounding them tend to be adaptations of regular practices during non-emergencies. Issues arise when the existing infrastructures, communications, and resources are disrupted, and application of those regular practices become unrealistic, impractical or unfeasible. While best practices should be the gold standard during times of crises, it is crucial to identify lessons learned and evaluate which are most beneficial *(3)*.

Current literature is largely focused on individual emergency events and short-term consequences, and tends to be limited to only one sector. The shift in paradigm from reactive to proactive Health EDRM, applied through the lens of an all-hazards approach and multi-sectoral perspectives, means evidence has to be systematically generated and validated in order to support a whole-of-society and risk-based approach *(2)*. Despite Health EDRM being at the intersection of heath and DRR, it is still an emerging field in both practice and academia (Chapter 1.2). It encompasses emergency and disaster medicine, DRR, humanitarian response, health systems resilience and community health resilience *(4)*. Furthermore, policies and programmes which cover the disaster management cycle are not always fully evidence-supported. For example, the Humanitarian Response Review *(5)* commissioned by the UN identified serious gaps in humanitarian action and made recommendations to ameliorate the situation.

Given that all humanitarian interventions occur in inadequate circumstances, a critical factor that compounds knowledge and evidence-generation is the partial or total collapse of the systems for routine information collection and analysis (Chapter 2.4). This is commonly observed in events of structural, social, and political instability *(6)*. The poor reliability and validity of information coming from compromised or incomparable information systems within an affected area further hampers the ability to monitor trends to determine the effectiveness of interventions, and be able to prioritize reliably and allocate resources efficiently (Chapter 2.7). There is also rarely sufficient real-time evidence to show whether the humanitarian situation is improving at the level of the crisis as a whole *(6)*. Table 2.6.1 gives an overview of health response topics which are currently supported by evidence; table categories are adapted from an invited paper published by the WHO Regional Office for the Eastern Mediterranean *(7)*.

**Table 2.6.1 Delineated interventional areas across Health EDRM by current status of the evidence base**

| Status: | Essential element of Health EDRM programmes: |
|---|---|
| **Operational and fully standardized** | Water and sanitation<br>Nutrition<br>Communicable diseases/surveillance/EWARS<br>Essential medicines<br>Partners/cluster coordination<br>Humanitarians accountability<br>Surveillance<br>EWARS/Outbreak investigation and control |
| **Not fully operational** | Assessments<br>Sexual reproductive health<br>Human rights and protection<br>Mental health<br>Education and training (humanitarian services providers)<br>Emergency preparedness<br>Risk prevention and mitigation<br>Hazards/vulnerability analyses<br>Emergency risk communication<br>Sexual harassment in humanitarian programmes and service delivery (staff and services' beneficiaries)<br>Psychosocial first aid<br>All-hazards approach |
| **Seriously deficient** | Real-time evaluation<br>Health systems resilience/recovery<br>Operational readiness<br>Ethics of research in health emergencies and disasters<br>Inter-sectoral coordination (health sector with others) |
| **Absent/Missing** | International Health Regulations (IHR 2005)<br>Disaster and development paradigm and linkages |

Unfortunately, it is wrongly assumed that all disaster risk management has been, and will be, based upon scientific evidence *(7)*. Further complicating the global application of knowledge is when the evidence generated is region-specific, the peculiarities may not be applicable to other cultures. Furthermore, where 'lessons learned' exercises and epidemiological research based on individual projects or crisis-led efforts do exist, and may be beneficial, a lack of systematic reviews makes it difficult to validate and assess the strength and direction of evidence for applicability in other disaster scenarios.

### 2.6.3 Research Rationale

Randomized trials are the most reliable way of generating evidence on the effects of interventions to guide and improve policy and outcomes in health (Chapter 4.1). Unfortunately, controlled experiments have inherent limitations and challenges for humanitarian settings, arising from, for example, the immediacy of urgent, life-saving health needs, security concerns, and marginalized status of affected populations make it difficult to gather informed consent. Nevertheless, repeated occurrence of humanitarian crises and use of remedial interventions do provide opportunities for ‘practice-based evidence’. However, this does not guarantee learning or improvements for the next crisis because no two crises are exactly alike. Cultural variations may also render interventions with documented successes in one crisis, inapplicable in the next. Furthermore, without explicit practice and training to create change, people may resort to old practices, even when these are not supported by evidence.

Systematic reviews can help to identify the most efficient and effective practices during different phases of the disaster management cycle. Providing standardized summaries of the vast volume of existing studies can enable evidence-based practices for preparedness and operational readiness plans to be introduced for on-the-ground responders, field coordinators, funding bodies and policymakers to incorporate into action *(6–8)*. This is especially relevant to disaster literature as it is largely made up of observational and descriptive studies (such as cross-sectional or case control studies) which may not determine causality *(9–10)*. Traditional hierarchies of evidence are heavily influenced by biomedical experimental designs, but some of these study designs may be unsuitable for disasters due to the lack of a controlled environment and ethical implications (Chapter 3.4). Gaps in practices can also be identified to guide future research, establish standardized methods of data collection and seek out methods for information dissemination *(6, 10)*. Systematic reviews can also help with the engagement of different sectors by identifying key roles in how they directly and indirectly impact health *(11)*.

### 2.6.4 What are systematic reviews?

Systematic reviews are robust studies which identify existing research to comprehensively answer a research question. This is done by methodically identifying eligible studies through critical appraisal to distinguish high from low quality evidence. The use of stringent guidelines and checklists can reduce selection and publication bias, validate statistical associations and causality and identify research gaps. The overall balance of evidence is essential for good decision making because a single study may be too specific in terms of its sample population, context, and the time it was undertaken to provide a more general application.

Three main types of systematic review are discussed in this chapter: quantitative synthesis (via meta-analysis), narrative systematic reviews and qualitative synthesis. Whichever type of review is chosen, two important sources of methodological guidance should be considered: Cochrane (Case Study 2.6.1) and the Joanna Briggs Institute *(12–13)*.

### Case Study 2.6.1
### Cochrane and the Cochrane Database of Systematic Review (CDSR)

Cochrane (formerly known as the Cochrane Collaboration) is an international organization that promotes evidence-informed health decision-making. It is internationally recognized as one of the leaders in the production of high-quality systematic reviews. It does not accept commercial or conflicted funding for any of its reviews and has four goals: producing evidence; making evidence accessible; advocating for evidence; and building an effective and sustainable organization. It produces well-respected and widely used guidance on the conduct of systematic reviews *(14)*.

As of January 2020, there were more than 8000 full systematic reviews available in the Cochrane Database of Systematic Reviews (CDSR) *(15)* which is available at www.cochranelibrary.com. There are five main types of Cochrane Review:

- Intervention reviews, which assess the benefits and harms of interventions used in health and social care and policy.
- Diagnostic test accuracy reviews, which assess how well a diagnostic test performs in diagnosing and detecting a particular disease.
- Methodology reviews, which address issues relevant to how systematic reviews and clinical trials are conducted and reported.
- Qualitative reviews, which synthesize qualitative evidence to address questions on aspects of interventions other than effectiveness.
- Prognosis reviews, which address the probable course or future outcomes of people with a health condition.

It is crucial that guidance is followed throughout the systematic review to maintain its rigor and to distinguish it from general or scoping reviews. Table 2.6.2 lists the key steps for a systematic review.

## Table 2.6.2 Steps and tools for a systematic review

| Process | Factors to consider | Common Tools and Resources |
|---|---|---|
| Defining the question | Specify the inclusion and exclusion criteria:<br>population, intervention, exposure, outcome, methodology, time of publication, time of data collection, language, geographic location, etc. | PICO mnemonic:<br>Problem/Patient/Population<br>Intervention/Exposure<br>Comparator<br>Outcomes |
| Conduct the literature review | A search criterion:<br>Search dates, language, location, study designs, synonyms, integrate/controlled vocabulary<br>Information source (Chapters 3.7 and 6.2):<br>Databases, funding agencies, trial registries, citation lists<br>Paywalls<br>Unpublished or grey literature<br>Reference management | General:<br>CENTRAL; EMBASE; EM-BIB; Google Scholar; MEDLINE; PubMed; PsycINFO; Scopus; Web of Science<br>Disaster specific:<br>DisDAT; EM-DAT; ReliefWeb<br>Reference management:<br>EndNote; Mendeley; RefWorks; Zotero |
| Apply inclusion and exclusion criteria | Remove duplicates<br>Apply specific to titles and abstracts<br>Obtain full articles for those potentially eligible<br>Further apply criteria to the full articles | PRISMA flow chart<br>ENTREQ<br>ConQual<br>COREQ<br>JBI Review's Manual<br>Cochrane Handbook *(14)* |
| Create data abstraction and analysis | Critically appraise the studies:<br>internal validity; study methods; participant number, reliability, (comparison) interventions<br>Analysis:<br>effect measure, significance, certainty (such as confidence intervals, p-value), pooled estimates, subgroup analysis (if appropriate) | AGREE II (appraisal)<br>R<br>SAS<br>SPSS<br>STATA<br>Qualitative tools |
| Presentation and findings | Risk of Biases within study<br>Directness of evidence<br>Heterogeneity<br>Publication bias<br>Journal, conference, oral presentations | GRADE Framework (Grading of Recommendations, Assessment, Development and Evaluations) |

### 2.6.5 Statistical meta-analysis

Quantitative synthesis (via meta-analysis) involves pooling the quantitative data from multiple independent studies to provide a *cumulative* aggregation of findings about, typically, the effects of an intervention compared with an alternative. In order to aggregate data, homogeneity is a crucial component, whether it is in terms of the population, intervention, comparators or outcomes covered. Regarding analysis, the results are often presented as a forest plot *(16)*, which shows the precision of each independent study and the cumulative findings. Case Study 2.6.2 provides an example of a meta-analysis of mental health and psychosocial support, including forest plots (Figures 2.6.1 and 2.6.2).

#### Case Study 2.6.2

#### The impact of mental health and psychosocial support interventions on people affected by humanitarian emergencies *(17)*

In 2017, a systematic review was commissioned by the Humanitarian Evidence Programme, a partnership between Oxfam Great Britain and the Feinstein International Center at the Friedman School of Nutrition Science and Policy, Tufts University in the USA. It describes the impact of mental health and psychosocial support (MHPSS) interventions on people affected by humanitarian emergencies, using both meta-analysis and qualitative synthesis methods.

Figure 2.6.1 shows the statistical meta-analysis of the impact of MHPSS on PTSD. Some studies show MHPSS interventions have a better impact than the control situation, while other studies suggest the reverse. The cumulative estimate of effect indicates that when the data from the 21 studies were pooled, the MHPSS programmes have a positive but small effect on PTSD. In contrast, Figure 2.6.2 shows that the cumulative estimate of effect of MHPSS interventions on anxiety, based on six evaluations, is neutral. This led the authors of the meta-analysis to conclude that these programmes have no impact on anxiety.

The review's narrative synthesis analysis on gender showed that "overall, the findings reported from these studies were mixed, with no clear pattern across types of intervention or outcome". It summarized eight studies narratively, comparing and contrasting their findings.

Qualitative synthesis was also conducted, and five themes were identified which can influence the effectiveness of MHPSS interventions: community engagement, sufficient number of trained MHPSS providers, experience of programme activities, benefits of group-based programmes, and building trust and supporting relationships. This identification of areas which are influential can help future interventions be better implemented and point out areas for greater emphasis by service providers.

**Figure 2.6.1 Forest Plot and Pooled Standardized Mean Difference (SMDs), 95% confidence interval (CI) and weight (W) of 21 controlled evaluations of the impact of MHPSS interventions on PTSD amongst people affected by humanitarian emergencies**

Measure: continuous: d (Hedges g)
Heterogeneity: Q = 206; df = 27; p = 0; $I^2$ =86.9%; tau-squared = 0.29
Random effects model: -0.463 (-0.689, -0.237)

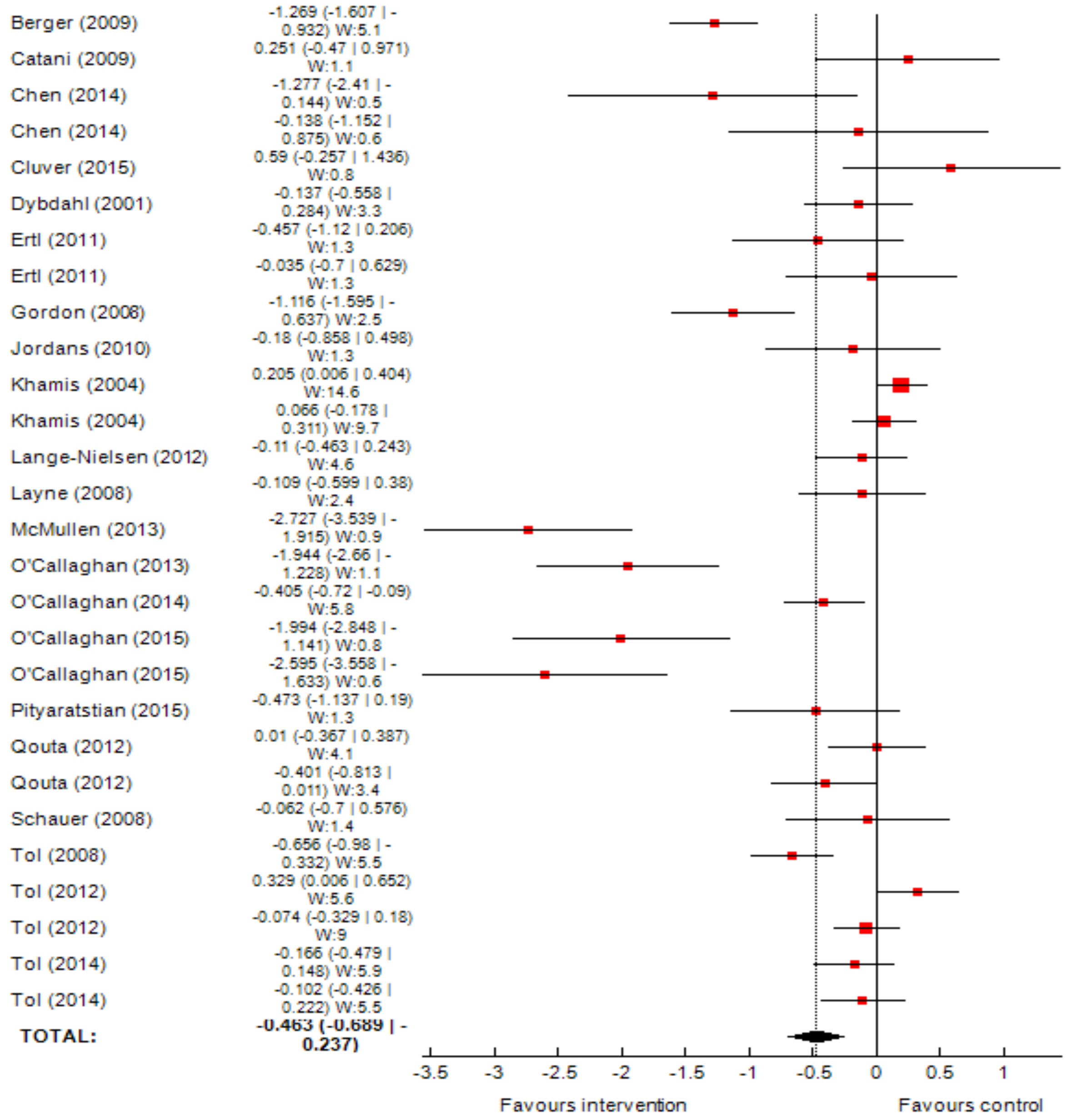
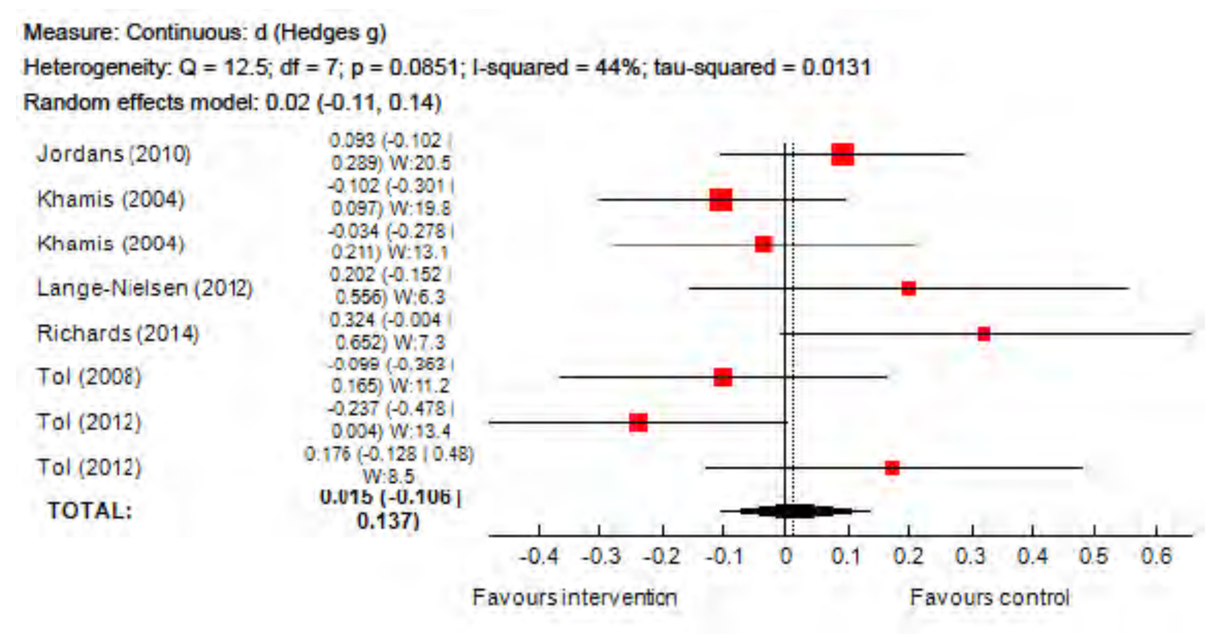


**Figure 2.6.2 Forest Plot and Pooled Standardized Mean Difference (SMDs), 95% confidence interval (CI) and weight (W) of 8 controlled evaluations of the impact of MHPSS interventions on anxiety amongst people affected by humanitarian emergencies**



In a forest plot (such as those in Figures 2.6.1 and 2.6.2), the solid vertical line represents no difference between the effects of the intervention and the comparator ('the trunk') and each study ('leaf') is shown to be either side of it. Each study is represented by a square to estimate the effect size for the intervention and a horizontal line for its 95% confidence interval. The cumulative estimate of effect, represented by the black diamond shape at the bottom of the figure, indicates the overall balance of the evidence from all pooled results of the individual studies.

Although most meta-analyses of the effects of interventions rely on randomized trials (Chapter 4.1), some use other evaluation designs that have varying risk of bias. These include quasi-experimental designs such as interrupted time series analysis, matched comparisons, regression discontinuity design, and difference-in-differences (Chapter 4.5) *(18–19)*.

## 2.6.6 Narrative systematic reviews

If the studies collected for a systematic review do not meet the criteria of homogeneity, they are often analysed using more descriptive and narrative methods of synthesis. Narrative systematic reviews use words and text (rather than cumulative statistical estimation) to summarize and explain the findings of the included studies. In effect, they ‘tell the story’ of the available evidence by describing and analysing the population, intervention, comparator and outcomes measured, and by undertaking descriptive and inferential statistics on each study individually. They might also help to develop a theory of how the intervention works, why and for whom, and can often provide preliminary synthesis of the findings of included studies *(20)*. This method of systematic review is prevalent in disaster literature due to the variety of stakeholders surrounding disasters, accessibility of data sources and a lack of comparable research tools.

## 2.6.7 Qualitative Synthesis

Evidence from qualitative studies are systematically reviewed using analytical methods of synthesis appropriate to qualitative methods and data *(21–24)*. Qualitative synthesis reviews evidence that has been gathered using in-depth interviews, focus groups, observational studies, ethnography, documentary analysis, oral histories, and case studies (Chapters 4.12 and 4.13). Rather than seeking statistical generalizations, it identifies common themes, concepts and principles across different studies *(25)*. It also gives detailed attention to the contexts in which studies were undertaken and tries to identify the contextual specificity of findings, including those that influence or determine the effectiveness of an intervention. By providing evidence from the viewpoints of providers and recipients of an intervention, local and cultural factors that influence the uptake, implementation, and impact of an intervention may be identified. Such information can help users to understand why, how, and under what conditions an intervention is likely to achieve the desired outcomes, as well as the barriers to, and facilitators of, achieving those outcomes.

## 2.6.8 Health elements: the current state of evidence

Most systematic reviews in Health EDRM use narrative or qualitative synthesis. This is largely because of the heterogeneity of the study methodologies and the small sample sizes, which limit the data available to be pooled. Even within the same topic, different definitions, measuring tools, and timeframes mean that studies cannot be directly compared *(26–27)*. While the lack of high quality data is often attributed to the volatile nature of disasters, it may also be due to the sensitive nature of the contents (such as gender-based sexual violence) or limited by language, whether the definition of terminology or differences in the language spoken/written. Some of the common themes and barriers to researching violence in disaster and humanitarian settings are described in Case Study 2.6.3.

### Case Study 2.6.3
### Existing evidence from systematic reviews on violence in disasters

The topic of violence is complex, especially when the trauma may still be ongoing. Studies on physical violence have found that men have repeated exposure to violent acts, whereas women and children tended to witness the violence – although this relationship changes for sexual violence *(28–29)*. Women are the main victims of gender-based sexual violence (GBV), but a scoping study showed there is insufficient evidence on how to support men who are sexually victimized *(30)*.

Research on child abuse and family violence may provide suggestions on prevention and intervention strategies. For example, parental trauma experience, substance abuse, mental disorder and history of child abuse were found to be risk factors for parents abusing their own children. The intergenerational cycle of violence, such as the use of physical discipline, coupled with environmental stressors such as disruption of family structure, food and shelter insecurity, and poverty all contribute to abusive behaviour *(31–33)*.

Common barriers for systematic reviews on violence are the lack of consensus and definition in terminology, which includes terms like 'torture', '(sex) trafficking', 'sexual exploitation', and abuse *(29– 30)*. Studies tend to be small because of the associated stigma and willingness to disclose such events and there is inconsistent use of validated outcome measurement tools making it difficult to compare, contrast and combine studies. Health outcomes of violence are also mostly about mental health, and physical health outcomes such as injury or disabilities are rarely reported; there are few evaluations of GBV interventions *(31, 34)*. A single study of sexual exploitation by humanitarian workers that studied peacekeepers across 36 international missions suggested that sexual exploitation and abuse was more likely to be reported for host countries with lower GDP per capita *(35)*.

A scoping search of systematic reviews published after 2005 using the key words: health, disaster, and emergencies, found that most were carried out in the Global North and only included papers written in English. Exceptions were on earthquakes (Asia), armed conflicts/humanitarian crises (Middle East and Africa), and H1N1 (China) *(36–38)*. Disasters that garnered wide media attention also dominated the available research, such as Hurricane Katrina, the 9/11 World Trade Center Attacks and the Wenchuan Earthquake. Reviews on natural hazards are largely focused on physical health outcomes, while human induced or complex humanitarian emergencies focus on mental health and psychosocial wellbeing. Only four meta-analyses were identified: two on mental health interventions; one on sexual exploitation and abuse among peacekeepers; and one on earthquake-related injuries *(17, 35, 38–39)*.

The most common contents in the reviews are health epidemiology and outcome. These include prevalence and incidence of disease, injury and mortality, particularly for natural hazards such as earthquakes, floods, and storms *(40–41)*. Mental health research has also seen a large increase in recent years, especially on the prevalence of PTSD. More attention has also been given to disaster responders *(42–43)*, and there has been a shift from research on refugees and internally displaced peoples in armed conflicts towards their health during seeking asylum and resettlement *(28, 44–45)*. Reviews on topics which have established response protocols, such as communicable diseases, have fewer recent systematic reviews unless they are about disease outbreaks (such as Ebola). Topics highlighted by the Sendai Framework, such as non-communicable and chronic disease, have garnered more publications but few systematic reviews and a reliance on observational studies *(46)*.

### 2.6.9 Barriers

One of the main barriers to conducting systematic reviews is the shortage of high-quality studies to review. A lack of transparent methodology, terminology definitions and rigorous criteria cause many studies to be excluded from the final analysis *(47)*. The difficulty of doing large studies is a constant disadvantage for research in a disaster, and this coupled with inconsistencies in the reported outcomes makes meta-analyses difficult or impossible. The availability of personnel to conduct field research is another barrier. In many cases, those who are responding to the disasters are also the researchers. This division of labour often means that research becomes a secondary priority *(9)*. To make it a top priority, dedicated research personnel should be established separately and well before a disaster's onset to ensure both priorities are met. As a field-based topic, Health EDRM should also consider publications from the grey literature, such as reports from non-governmental and inter-governmental organizations (Chapter 6.2).

This may be particularly true for research done within organizations, because the findings of such research are usually kept in-house. Dissemination through academic journals and conferences are primarily channels for researchers, and systematic reviewers will need to look for relevant evidence in other communication channels, including in languages other than their own.

### 2.6.10 The future of systematic reviews for Health EDRM

The future of systematic reviews for Health EDRM lies in identifying the most efficient methods of data collection, which includes having standardized data collection tools. Since systematic reviews provide a less biased and more statistically powerful analysis of currently available evidence, there should also be a consensus as to how often reviews on the same topic should be updated. Research should be tailored to the needs of the affected communities. For example, mental health is a broad topic that has international traction, and the focus on PTSD may exclude other aspects of mental health (such as anxiety-related diseases or other psychosocial comorbidities) that are associated with exposures to multiple hazards.

## 2.6.11 Conclusions

Humanitarian crises are growing in frequency, magnitude, and scale, in addition to the increasing globalization connectivity, and premature urbanization. When coupled with warnings over the hastening of adverse impacts from climate change, there is an increasing imperative that remedial elements and corresponding interventions along the emergency continuum are evidence-based, predictable, standardized, and afford the maximum efficiency and effectiveness. There also needs to be accountability if and when the interventions are not properly implemented. However, the evidence base for Health EDRM is currently variable at best, affecting standardization and predictability and which hampers accountability. To have a standardized Minimum Data Set for core outcomes will greatly facilitate interoperability across different health systems and nations by hastening data availability. That in turn will lead to a more optimal application of sound and effective interventions in health emergencies, All of which should be based on reliable and timely evidence from systematic reviews of good quality research.

Despite limitations and challenges posed by paucity of information, and concerns over the reliability and validity of information available, a large body of literature has been produced on project and crises-specific interventions covering various elements of Health EDRM and their impact. Systemic reviews need to be done to assess the strength, relevance, and utility of this body of literature for improving Health EDRM.

## 2.6.12 Key messages

- **Many challenges hamper the generation of evidence and its accurate and consistent application in Health EDRM. Practitioners who are aware of evidence limitations may not have the necessary training or skills to design, plan, implement and evaluate their programmes. They may also lack the training to discern programmatic and practice-based problems that could be turned into research questions for new studies (Chapter 3.5).**
- **People in low-income, resource-poor countries and settings may disproportionately suffer from the ‘double jeopardy’ of lacking the critical mass of trained researchers and practitioners, coupled with limited or non-existent opportunities for interaction between researchers and practitioners in Health EDRM.**
- **Strong leadership will be required from global and regional entities, including donors, with a strong stake in Health EDRM to bring together the main groups required for the generation and use of evidence: the Health EDRM practice community to identify needs and problems requiring research; the academic sector to conduct high quality research; and agencies and donors to bridge the science into practice and application gaps.**
- **Systematic reviews provide the means to bring together existing evidence to inform these processes and to place the findings of new studies in the context of the totality of the evidence. They will allow decision makers in Health EDRM to make use of the best available evidence.**

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# 2.7 Prioritization of research

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## 2.7.1 Learning objectives

To understand the key factors to consider when preparing, developing and evaluating a research prioritization exercise in health emergency and disaster risk management (Health EDRM), including:

1. The importance of careful selection of priorities for research.
2. Practical steps in setting priorities.

## 2.7.2 Introduction

Research prioritization is usually defined as an interpersonal activity that leads to the selection of the topics to be studied and the methods to be used in research *(1)*. The results of the exercise do not always directly match the final decisions that are made by governments or organizations as to what research to conduct, but they can be useful for guiding such decisions. A level of flexibility may be needed to be responsive to important political issues that arise, meaning that pre-set priorities may be amended to take account of the situation.

In Health EDRM, priority setting might be done at the level of the research group trying to develop a specific research question, or at an organizational level – such as within a nongovernmental or governmental organization or UN agency that is trying to develop a broader research area, which might then be refined to one or more specific research questions.

The objective of a research prioritization exercise depends on the context in which it is conducted, the political, social and organizational processes that led to its initiation and the managers, professionals, practitioners, policy makers and ultimate beneficiaries of the process (often referred to as stakeholders). Some examples in Health EDRM include:

- Evidence Aid's priority setting exercise to identify thirty priorities for up-to-date systematic reviews of the effects of interventions, actions and strategies on health outcomes, which would be particularly relevant to those involved in disaster risk prevention, preparedness, response and recovery (Case Study 3.5.3 in Chapter 3.5) *(2)*.

- WHO's gathering of healthcare practitioners to identify key research priorities around the role of nurses and midwives in emergency responses *(3)*.

There is no consensus as to the scope or depth of a research priority. It may be broad (such as "more research on tropical diseases") or specific (such as "the cultural drivers of the spread of the Ebola virus in the DRC in 2019"). However, there is consensus about various elements that are likely to support a quality research prioritization exercise (Figure 2.7.1). These elements can be grouped into three steps: things to do *before* the priority setting exercise (preparation), things to do *during* the exercise, and things to do *after* the exercise.

**Figure 2.7.1 Elements to support a research prioritization exercise**

| | | | | |
|---|---|---|---|---|
| **Step 1** Preparation | a) Leadership team | b) Understand context and collect necessary data | c) Identify and engage with stakeholders | d) Collecting background information |
| **Step 2** Shaping a Priority Setting Exercise | a) Identify research questions | | | |
| | b) Deciding on use of criteria | | | |
| | c) Ranking the research questions | | | |
| | d) Disseminate/implement priorities research questions | | | |
| **Step 3** After the Priority setting exercise | a) Conduct prioritized research projects | | | |
| | b) Implement findings of research projects | | | |
| | c) Evaluating impact of research findings | | | |
| | d) Report and Publish the priority setting exercise | | | |
| | e) Evaluate the process and outcome of the exercise | | | |
| | f) Feed the results back to revise future exercises | | | |

## 2.7.3 Step 1: Preparing for a research prioritization exercise

### Step 1a Leadership team

The prioritization exercise will need a team to design, lead and monitor its implementation. The team needs to identify people, skills and resources required to complete the project. Technical skills, such as managing information, visualization or effective data collection, are important. However, interpersonal skills are also crucial, including effective communication, relationship building with those involved in disaster risk management including response, disaster research and the ultimate beneficiaries of the research and service, coordinating and chairing discussions, and the ability to analyse political situations in order to decide on appropriate strategies and tactics.

### Step 1b Understand context and collect necessary data

Before embarking on a new prioritization exercise, it is important to understand the context for it, including whether there are any other similar or otherwise relevant exercises, any high level strategic priorities that have already been set, or any critical political decisions that have been made, which should influence or inform the exercise.

Viergever and colleagues *(4)* categorize the contextual issues affecting the process of research prioritization as available resources, focus of the exercise, values of those involved and the underpinning health, research and political environment. For example, a specific contextual issue relevant to Health EDRM research is the underlying causal factor that might influence how badly a disaster affects the community. This includes the degree of exposure and vulnerability of the society (Chapters 1.3 and 3.2) *(5)*.

### Step 1c Identify and engage with stakeholders

As part of the preparation for the prioritization exercise, the team needs to identify who should be involved in setting the priorities, including the people, organizations and governments, remembering that each of these has many different layers. For example, government might be at the local, regional or national level. WHO's report on research for health also mentions civil society organizations, philanthropic bodies and industry as important stakeholders in a prioritization exercises *(6)*. Others who might need to be involved include patients, the general public, universities and research institutes.

Some key questions that should be considered in choosing the individuals to engage in the process are:

- Who are the individuals who will benefit or use the results of the prioritized research?
- Who are the individuals who have knowledge and oversight of the major issues that are likely to have an impact on those affected, or have influence and impact (such as politicians or managers of humanitarian aid organizations)?
- Who are the individuals who have direct knowledge of what happens in the field and in routine practice (such as healthcare workers in disaster areas, those who were directly affected and those providing support for them after a disaster or those who have local knowledge)?

- Who are the individuals who have a key role in supporting or implementing the research (such as academic organizations, philanthropic bodies and industry)?
- Who are the individuals who have a key role in moving the results of the research into policy and practice (such as healthcare professionals and workers, politicians and policy makers)?

In order to ensure proper engagement of stakeholders in the process, it is important to consider how they are involved, to ensure true involvement and avoid tokenism. The series of questions in Table 2.7.1 can help to guide these decisions *(7)*.

### Table 2.7.1 Using an equity lens to set research priorities: questions to consider

1. Are a variety of stakeholders who might be affected by the choice of research topics involved in the prioritization process (such as people who differ in age, sex, sexual orientation, disability, ethnicity, religion, place of residence, occupation, education, socioeconomic status, and social capital)? In which steps are they involved? It is important to have an audit process to ensure that those communities impacted are included in the process.
2. Does the prioritization project consider reducing inequity as part of its objectives?
3. Are the methods and tools selected to identify prioritize, implement, disseminate and communicate research topics understandable, transparent and relevant for different stakeholders? For example, if the target population is multi-lingual and the researchers only use tools that are in English, this will not provide equal opportunities for the whole population to be involved – translation or using images might help to address it. It is important to consider that the readiness, availability and tendency of the stakeholders to respond to the survey or data collection is variable. Some might respond quickly and in a timely manner while others may need more time. Some may require evidence that their contribution is taken seriously or require support and empowerment before dedicating time and resources to contribute to the process.
4. Have specific strategies been considered to minimize the barriers to participation by disadvantaged or less accessible populations (this can be physical accessible such as population living in remote areas or other aspect of accessibility such as population that speaks a less known or used language)?
5. Does any situation analysis (such as evaluating current research coverage, identifying gaps and evaluating healthcare needs) consider the differences in the prevalence, severity and urgency of health problems along with potential differences in the impact or value of the interventions assessed across different subgroups?
6. Do the criteria for prioritization consider potential differences in the severity and urgency of health problems in disadvantaged populations or less accessible groups, as opposed to the health problems in privileged populations? Criteria refer to factors that individuals use to rank the research topics and questions. These criteria might be predefined or defined during the process.
7. Do the criteria for prioritization consider the potential differences in the impact of an intervention in disadvantaged populations, as opposed to the problems in privileged populations?

8. Do the criteria for prioritization consider that different population groups might have different values and preferences? This does not only refer to individuals' values with regard to health issues but the larger impact of research on cultural values.
9. Are different stakeholder groups provided with an opportunity to provide feedback and appeal the methods and results of the prioritization process?
10. Did the prioritization result in research topics that are relevant to disadvantaged groups? This can be topic areas that are relevant to the daily life of disadvantaged groups (on an individual level) or reducing inequity (on a community level) – or topics that cover both areas.
11. Does the dissemination and implementation strategy increase the likelihood that funders and research institutes become aware of the prioritized research topics and consider them as part of their research agenda or strategic planning?
12. Does the dissemination and implementation strategy increase the likelihood that prioritized research topics of relevance to disadvantaged groups get funded and conducted?
13. Does the dissemination and implementation strategy increase the likelihood that researchers who work with disadvantaged groups will conduct or get involved in the prioritized research projects?
14. Does the dissemination and implementation strategy increase the likelihood that disadvantaged groups or decision makers or practitioners who work with disadvantaged groups get involved in the prioritized research?
15. Does the dissemination and implementation strategy increase the likelihood that policy makers and decision makers who work with disadvantaged groups will use the findings from the prioritized research?
16. Did the results of the prioritized research topics change policies, legislation or clinical practice in favour of disadvantaged groups?
17. Did the appeal and enforcement strategy increase the likelihood that disadvantaged groups or decision makers, researchers and practitioners who work with disadvantaged group will provide feedback and comments on the prioritization process or its results?

For all the individuals involved in the priority setting process, it is important to consider how they may have different values and preferences based on their characteristics, background, knowledge and skills and how these will be represented, including different socioeconomic or racial groups. The acronym PROGRESS PLUS can be useful in identifying pockets of vulnerabilities within the beneficiaries of the research. PROGRESS PLUS defines axes of potential disadvantage: Place of residence, Race/ethnicity/culture/language, Occupation, Gender/sex, Religion, Education, Socio-economic status, Social capital and other characteristics ('Plus') such as sexual orientation, age and disability.These characteristics identify whether certain communities of populations are disadvantaged due to "social, political and legal structures and processes". During the preparation phase for the exercise, the lead team should identify all groups and communities, including disadvantaged groups, that are relevant to the topic area and ensure that individuals involved in the priority setting process represent those dimensions *(8)*. Case Study 2.7.1 highlights how the values and preferences of stakeholder groups can differ.

### Case Study 2.7.1
### Values and preferences of different stakeholders: research priorities for mental health and psychosocial support in humanitarian settings

A research prioritization exercise for mental health and psychosocial support in humanitarian settings was conducted in the Republic of Peru, Uganda and Nepal, with 114 participants. These included policy makers, academic researchers and humanitarian aid workers; covering a range of disciplines (psychiatry, psychology, social work, child protection, and medical anthropology) and organizations (governments, universities, non-governmental organizations and UN agencies).

The team conducted focus groups with each stakeholder group separately, to identify their priorities, before comparing and contrasting these priorities.

Although some priorities for research were similar between the groups (such as the prevalence and burden of mental health and psychological distress), there were areas of disparity. For example, academics gave more priority to research about improving methods and processes and obtaining long-term results, while aid workers and policy makers were more interested in projects that could be interpreted quickly and would have immediate results. Some aid workers even raised concerns that research could be a waste of time. This suggests that it may be important to identify and prioritize research questions that include both the long-term impact of Health EDRM and short term results in order to increase engagement with field and aid workers *(9)*.

People who study or conduct research prioritization often fail to report in adequate detail how the values of individual stakeholders affected the interpretation and use of data in the process. For example, the US National Academy of Medicine Committee on Health Care Technology recommends collecting or estimating “data for the prevalence of specific conditions, the unit cost of the relevant technology, various uses of the technology, the burden of illness addressed by the technology, and the potential of the results of technology assessments to affect health outcomes and costs”. The difficulty with this approach is that the collection, analysis and presentation of data are buried under layers of assumptions and value judgements that may not account fully for the true values and perceptions of different stakeholders. This variation can justify different decisions about collecting or analysing data. For example, different approaches to defining the burden of illness can lead to different decisions on research priorities. It is therefore important that the reporting of the results of the prioritization exercise should be as detailed and specific as possible about the data that were used, the methods that were applied and who was involved in different stages of the process *(10–11)*.

#### Step 1d Collecting background information

Research prioritization should be evidence-based and guided by reliable information. When preparing for a prioritization exercise, it is important to identify and access relevant routinely collected data and studies that have already been conducted, and use interviews, case study materials or surveys to gather up-to-date knowledge, information from the stakeholders and missing information. The most difficult part may be to identify the key operational questions from field workers and examples about what has helped or hindered them in past responses, as field workers will be under pressure to deal with the imminent needs of those affected by an emergency or disaster and research is unlikely to be a priority for them. This highlights how research into the preparedness of different parts of the disaster response system may be a priority. For example, a paper by Rosner and colleagues describes in detail how the preparedness to shift public health services in response to an emergency helped in the 9/11 attacks on the World Trade Centre, how the different services responded afterwards and how this might be improved in future *(12)*.

Ideally, part of the exercise should include systematic searches to explore whether the identified research questions are indeed real research gaps or needs (Chapters 2.6, 3.6 and 3.7).

The prioritization process should also consider current sources of research funding (Chapter 6.3) and research capacity for the specific topic and setting. This can also provide information on research that has been done or is currently being conducted, what advances are most achievable, and what is most likely to be supported in the future. Moreover, it can highlight reasons for research gaps (Chapter 3.7) and how these might be addressed. For example, some donors and funders might place restrictions on how their money can be used and research gaps may exist because of these restrictions. It may also be important to consider whether the focus of the research should be on a specific event or type of emergency or disaster or use a holistic approach to study the impact of emergencies and disasters generally. For example, some areas in the Philippines are dealing with repeated disasters of different types that impact on efforts to rebuild the community *(13)* .

### 2.7.4 Step 2: Shaping a priority setting exercise

A simple way to conduct a research prioritization exercise is to bring people with relevant knowledge together in a meeting and help them to achieve consensus on the most important things to study. However, these group conversations are known to have strong biases and errors (due to undue influence by individuals who are most vocal, for example). Therefore, tools and methodologies have been developed to guide organizers of priority setting exercises. Examples of tools are object mapping and the use of images to facilitate storytelling *(14, 15)*.

The methodologies that have been developed to guide priority setting all adhere to the same set of steps, depicted in Figure 2.7.1. This section describes steps 2a, 2b and 2c, which help to make the prioritization process itself more systematic, transparent and evidence-based.

**Step 2a Identifying research options**

The first step of the priority process itself is to identify all relevant research options within the scope of the priority setting exercise (bearing in mind that the team should have already defined the scope of the exercise under Step 1: Preparation). There are many different ways in which the team can identify research options.

Conduct a literature review in the field that is the scope of the priority setting exercise on:

- the current state of knowledge
- current research
- research gaps
- previously established research priorities.

Ask stakeholders what they think are research options:

- in questionnaires or interviews ahead of the meetings where consensus on a list of priorities is established
- at the start of those meetings
- or a combination of these two.

It can be elegant to include larger groups of stakeholders in the early stages of the priority setting exercise to ask them about research options. For example, in a research priority setting exercise for a health condition, the organizing team might send out surveys before any meeting is organized to ask patients, healthcare practitioners and researchers to suggest research options. The options that arise from these surveys might be organized by the team according to different levels of granularity. Interviews could be held to deepen descriptions of stakeholders' views on the research options and a literature review could provide a stronger evidence base for them. The list of research options that follows from this might then be reviewed, refined and finalized during a meeting of a smaller group of stakeholders.

### Step 2b Deciding on use of criteria

The team leading the prioritization exercise might decide to define and use criteria to prioritize each research option. These criteria would help all those involved in the exercise to differentiate and rank topics. The use of criteria is generally considered to be good practice in priority setting exercises. The organizing team might predefine the criteria based on literature review or involve stakeholders in setting these criteria. In the latter case, it is advisable to ask stakeholders what factors informed their decisions. Examples of criteria include whether alternative interventions are available, budget impact, health impact, amount of controversy around the intervention or the topic area, disease burden, economic impact, ethical implications, legal implications, psychosocial implications, underlying evidence, expected level of interest and variation in rates of use of the intervention *(15–16)*. If multiple criteria are used to inform the prioritization decisions, a performance matrix might be a useful approach to frame and guide the process, and to rank the priorities and guide discussions in a consensus meeting *(17)*.

### Step 2c Prioritizing the research options

There are a variety of methods for asking individuals and organizations (stakeholders) to 'judge' each research option and to achieve a list of research *priorities*. These include surveys (such as of those affected by a disaster, practitioners, policy makers or managers), consensus methods (such as Delphi), face-to-face meetings and participatory workshops to discuss and agree on the priorities *(18–19)*. Often, a combination of these methods is used. As part of the development of the process, the prioritization team need to decide which individuals should have their knowledge and values recorded and incorporated in the process and whose knowledge and values need to be used to define key decisions in the process (such as ranking and prioritization). The latter might be used to shape the group that will be involved in choosing the final set of priorities.

It is important to be aware of the key issues that can affect the dynamics of stakeholder interactions during the research prioritization process. Developing good relationships with individuals can help to understand their interests, values and preferences as well as power relations between the different groups and how this can affect stakeholder engagement. If a consensus meeting will be held, it is recommended to have an independent and experienced facilitator to manage the meeting who is aware of these issues *(1, 20-21)*. It may also be important to have a mechanism in place to identify and report financial and non-financial conflicts of interest of stakeholders.

The organizers of a priority setting exercise need to consider that attending meetings may be difficult financially for some stakeholders and that this might affect their presence and attendance. Some stakeholders might be less comfortable with disagreeing with some of the other participants in meetings for fear this might affect their future working relation or access to funding.

### 2.7.5 Step 3: After the priority setting exercise

After the priority setting exercise, six things are important:

**Step 3a Conduct the prioritized research projects:** because priority setting exercises are intended to ensure that the right research is conducted, it is important to consider how the prioritized research projects may be best initiated.

**Step 3b Implement the findings of research projects:** research can sometimes be “blue-skies research”, but more often research is done to inform health practice or policies directly. A plan should be made as to how the findings of the prioritized research projects may be translated into practice, policy or both.

**Step 3c Evaluate the impact of research findings:** a plan is also needed as to how the research that will be done as a result of the priority setting exercise might be evaluated.

**Step 3d Report and publish the priority setting exercise:** it is important to both disseminate the results of a prioritization exercise and ensure that the relevant researchers and funders have access to the results and a clear report of how the exercise was done. There is a reporting guideline (Chapter 6.6), REPRISE, to help with this *(22)*.

**Step 3e Evaluate the process and outcome of the exercise:** the evidence base for the quality of priority setting exercises will be improved if more exercises are evaluated systematically. For example, papers by Viergever and colleagues *(4)* and Nasser and colleagues *(7)* provide frameworks that can inform the building and implementation of an evaluation framework. This includes looking back at the process and outcomes of the priority setting exercises and asking: What went well? What could have gone better? What should the organizers of the next priority setting exercise on this topic do differently? What lessons were learned? This information should be included in the report or publication.

**Step 3f Feed the results back to revise future exercises:** priority setting is an iterative process that might keep running and changing, based on what research gaps remain and need to be addressed. Therefore, the prioritization exercise may need to provide opportunities for periodic review of the priorities that were agreed, and for appeal and feedback on these. Such reviews also provide opportunities for stakeholders to challenge the results of a prioritization exercise, or provide feedback to the group on the priority decisions they made, which will improve the acceptability and, as a result, legitimacy of the exercise. Thus, there should be a plan as to when the priority setting exercise will be repeated and how the information gleaned in Step 3 will be used to inform future exercises.

Lastly, a note on funding: prioritization exercises may be used to inform decisions about the allocation of funding that might otherwise be used on other aspects of Health EDRM. This makes it especially important to demonstrate accountability towards the stakeholders and evaluate the success of the exercise.

### 2.7.6 Conclusions

Several different approaches have been used to set priorities for research to adapt to the variety of contextual issues for which these priorities are needed. The approach to take depends on the objective of the prioritization exercise, underlying principles, ethical frameworks, and social, political and contextual issues. There are also different ways to categorize the purpose of the prioritization exercise. It might be categorized as identifying current uncertainties or be more future oriented, seeking to address issues that will arise in the future.

Some have defined steps in research prioritization as predominantly technical, including the interpretive and consultative methods used to identify data and encourage stakeholder's involvement. However, research prioritization exercises do not always clearly belong to one category. For example, those that emphasize involving stakeholders and using qualitative methods to gather information from them, will probably still use quantitative data to inform the decision-making process, while those that are predominately data driven (for example that emphasize the value of information analysis) will require people to make value-driven assumptions when interpreting these data to inform their decision making *(1, 23)*.

Across health research generally, it is important to identify the topics that are the highest priorities for new studies. This is if anything even more important in Health EDRM, where funding and resources put into research might otherwise have been used directly for risk prevention, preparedness, response, and recovery to strengthen resilience. In setting the priorities for new research, it is important to follow a process that is equitable, involves all the key stakeholders and uses an evidence-based approach to identify the areas of greatest need that are most amenable to research. This chapter has outlined some of the key steps for doing this.

## 2.7.7 Key messages

- **Prioritization of research in Health EDRM will help ensure that the research that is most needed gets conducted and make efficient use of resources that might otherwise be used for implementing interventions.**
- **Those undertaking prioritization exercises should use an evidence-based approach and ensure that key stakeholders are involved. Several methodologies are available to help do this.**
- **Reports of prioritization exercises should be clear about the outcomes, the methods used in the exercise, the underlying assumptions made before or during the process to support the decision making process (such as political, social and economic views underlying support or funding decisions), and how the various sources of information were used, in order to allow those who might act on the priorities to judge the quality and relevance of the exercise that led to them.**

## 2.7.8 Further reading

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# Determining the scope of your study

# 3.0

# 3.1

# Asset mapping to consider outcome measurement and stakeholder engagement

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## 3.1.1 Learning objectives

To understand key factors to consider when using asset mapping to support research into health emergency and disaster risk management (Health EDRM), including:

1. The tradition of community health outcome measurement in disaster research.
2. The concept of asset literacy and how it can be leveraged as an outcome of asset mapping to support disaster risk reduction.
3. The value of engaging key stakeholders from the outset in order to develop a common vision of health deficits and assets and identify solutions to maximize community resilience.
4. The use of an asset lens in outcome measurement studies in pre- and post-disaster contexts.

## 3.1.2 Introduction

Communities affected by disasters may experience extensive impacts to the health and well-being of the population. Disasters also affect the economy, infrastructure and the environment. The impacts are not all inherently negative, and positive impacts may result from a disaster at the individual-level (such as post-traumatic growth) and the community-level (such as strengthening of social connectedness and safer or greener structures). In addition to reducing future risk, this underscores the essence of building adaptive capacity before a disaster and 'building back better' after a disaster (Chapter 1.3) *(1–2)*. All these issues need to be considered when planning and using research in Health EDRM. Furthermore, recognition of the need to understand the complexity of different types of impact in turn prompts recognition of the need for diverse research approaches and methods that can account for existing and emergent capacity in outcome measurement.

Disaster research has traditionally involved methods to develop risk and vulnerability profiles (Chapters 1.3 and 3.2), map hazards and assess adverse outcomes following events. Tyler and Moench *(3)* refer to this paradigm as ‘predict and prevent’ (to which we may also add ‘protect’) and underscore its limitations based on anticipation, surveillance and reaction to threats rather than building resilient systems. Further to this deficit-based approach, measurement of outcomes and associated predictors should be based on wider considerations, including protective factors and positive consequences arising from disasters.

The disaster literature has traditionally focused on financial or physical infrastructure, when referring to assets. However, as the field of DRR has become more interdisciplinary, understanding of assets has broadened toward inclusion of critical social infrastructure and a more balanced approach to understanding resilience, which focuses not only on risk and deficits, but also on physical and social assets within a community that can support resilience *(4)*. Here, resilience broadly refers to the intrinsic capacity of an individual or community to resist, adapt and recover after experiencing a disturbance, such as a disaster *(5)*.

This chapter describes asset mapping as it relates to both outcome measurement and stakeholder engagement, and the relevance of asset literacy from a public health perspective. The intent is to highlight the importance of outcome measurement that focuses not only on deficit-oriented measurement, but also on community assets to support resilience. The role of stakeholder engagement in supporting asset literacy is also discussed. Case Study 3.1.1 illustrates how these concepts fit together by highlighting a community initiative introduced to measure asset-based outcomes, map community assets and engage stakeholders in the monitoring of long-term impacts and the community recovery following the Lac-Mégantic train derailment and explosion in 2013.

### Case Study 3.1.1
### Psychosocial Impacts of the Lac-Mégantic Train Explosion

On 6 July 2013, a train carrying 72 cars of oil derailed in downtown Lac-Mégantic in the Estrie region of Quebec, Canada. The derailment provoked a major conflagration and a series of explosions. The disaster resulted in 47 deaths, the destruction of 44 homes and businesses, the evacuation of 2000 citizens (that is, one third of the local population) and an unparalleled oil spill. The disaster caused major human, environmental, and economic impacts *(6)*. In the first years after the disaster, the Estrie Public Health Department undertook several actions, including monitoring physical health and psychological consequences. Four cross-sectional health surveys (2014, 2015, 2016, 2018) were conducted by the Public Health Department and the University of Quebec in Chicoutimi among large and representative samples of adults living in and around Lac-Mégantic, gathering data on a variety of physical and mental health outcomes. Findings from the first two surveys in and around Lac-Mégantic revealed that about one in six adults were considered as having been intensely exposed to the disaster. Steep gradients were observed in the prevalence of adverse psychosocial outcomes as a function of intensity of exposure to the train derailment. The findings showed persistent and widespread health needs, such as PTSD, anxiety, and a higher proportion of people seeking mental health services *(7)*. In addition to adverse psychosocial outcomes, various asset-based outcomes were considered in the surveys. This found, for instance, that intensely exposed adults were less likely to report optimal mental health in 2015 (as opposed to low exposed ones), suggesting that health assets can weaken with time among people directly impacted by a disaster, especially in the absence of adequate support and services.

Given the magnitude of the disaster, the Estrie Public Health Department hosted a collective reflection day, bringing together local stakeholders to discuss possible solutions for the health and well-being of the community *(8-9)*. A defining moment of this day was the asset mapping activity through which participants constructed together a historical timeline that traces key milestones in the recovery of their community and recognizes the progress made. By highlighting a series of interventions and initiatives previously implemented by social workers and other partners, the group identified benefits at the individual and community level, as well as features common to the actions that created positive effects.

During the reflection day, it became apparent there was a need to initiate a positive campaign to highlight the strengths of the community. A community-based participatory research approach was chosen to address this need, and an asset-mapping project using a Photovoice method was designed with the purpose of allowing local citizens to explain the aspects that make their community an attractive place to call home and to map assets that support resilience within their community (see also Case Study 4.12.1 in Chapter 4.12). Following this six-month initiative, the group hosted two exhibitions to share their photos and ideas with the public, including politicians and decision-makers. These events were an opportunity for the participants to enhance collective asset literacy and showcase the assets in their community and a collective vision for the community going forward.

Fostering community engagement was a hallmark of the physical, economic and social reconstruction process in Lac-Mégantic. The importance of identifying and leveraging existing assets or resources at the community level, including local health agencies, and working with existing capacities were strongly valued. A better understanding of the local needs and capacities gave residents in Lac-Mégantic the opportunity to become increasingly involved in personal or community projects, as well as collective events. Although the disaster has left its mark, the local community is gradually adapting to its new reality. The asset-based approach contributed to this “new reality” and emphasizes the importance of social capital to activate individual and community resilience in post-disaster contexts.

The outreach team published a report five years after the tragedy to highlight the different strategies used in this community to mobilize the local community in the post-disaster landscape *(10)*. All these initiatives have contributed greatly to empower citizens and mobilize the community of Lac-Mégantic and surrounding areas.

### 3.1.3 Outcome Measurement

In their asset model for public health, Morgan and Ziglio *(11)* present a model showing the theoretical base of salutogenesis (saluto = health; genesis = origin of) as the foundation for asset-based health promotion. They emphasize the need for enhanced outcome measurement methods, with a caution toward using a traditional deficit-oriented approach, which tends to focus on what produces disease and psychosocial problems (rather than health and well-being). Over the past few decades, many positive health concepts have emerged in science (such as self-efficacy, resilience, social support or participation, civic engagement). Public health actors, including those involved in disaster research or disaster risk management, are invited to consider and assess such asset-based outcomes (in addition to deficit-based ones) and to adopt more broadly a "salutogenic" orientation.

Outcome measurement is a core activity of public health and Health EDRM. It is used to assess prevention and preparedness programmes and initiatives, response and recovery activities, and community health impacts in the months and years following a disaster (see also Chapter 2.2). Measuring community health outcomes is critical for understanding how a population is impacted over time, allowing public health and the broader health system to develop and tailor programmes and services to meet the changing needs of the population *(12)*. Adverse impacts on physical and mental health are common outcome measurements for community health, requiring both short- and long-term monitoring *(7)*.

By causing body stress, mental workload, losses and disruption, injuries and lesions, and changes in lifestyle habits, disasters often lead to adverse impacts for individual and community health and well-being, over the short and long term. The acute consequences of large-scale traumatic events vary according to disaster type. Primary health problems are directly caused by disaster action (such as wounds, intoxication due to toxic fumes). Secondary health problems can also be observed, including infections, accidents, or dysfunction of physiological functions associated with disaster-generated stress (such as hypertension as a result of overexposure to stress) *(13–14)*. Finally, various somatic symptoms may affect victims of a disaster. These include sleep disorders, headaches, fatigue, abdominal pain, and shortness of breath. The prevalence of somatic symptoms, which can last several years, have been found to range from 3% to 78% *(15)*.

In addition to acute consequences of disasters (mostly physical health consequences), the population burden of mental health problems in the aftermath of disasters is substantial and potentially of long duration (Chapter 5.1) *(15–16)*. PTSD is the most common mental health outcome studied in a post-disaster context *(17)*. One review of the literature estimates the prevalence of PTSD to be 30-40% among direct victims, 10-20% among rescue workers, and 5-10% in the wider community *(18)*. Given the high prevalence of PTSD after a disaster, more research is needed to evaluate a broader range of psychosocial outcomes such as psychological distress, major depression, generalized anxiety disorder, panic disorder, phobia, complicated grief, maladaptive behaviours (including alcohol and drug abuse), suicidal ideation, but also positive outcomes (including sense of belonging to the community, sense of coherence, positive mental health, and post-traumatic growth). Exposure to a disaster can also have a positive long-term effect on the beliefs and values of certain individuals and create a stronger sense of family, social capital and collective solidarity. Some individuals may even discover personal strengths which had been previously untapped *(19–20)*.

Communities struck by a disaster caused by natural or human-induced hazards need to learn to assess the evolving health of the population, in order to implement upstream and downstream actions that can properly respond to the needs of the individual and wider community. To do this, short- and long-term monitoring of both physical and psychological consequences through various quantitative methods is essential. A variety of data sources can be used for monitoring population health over time, including routinely collected information, such as medical and administrative databases and surveys, as discussed in Chapters 2.2 and 2.4. Surveys can be either clinical- or community-based, and cross-sectional or longitudinal in nature. Ideally, both exposed and unexposed individuals should be monitored over time. Indeed, having a control or comparison group allows investigation of the association between exposure to the disaster and health effects observed.

Regardless of the data sources chosen, in an ideal world it is important to ensure a complete set of measures is monitored over time, including physical health, psychological health, health behaviours, perceptions, access to services, social support, risk and protective factors, and so on. Negative and positive consequences should be considered. For example, following a major flood, researchers may wish to examine temporal trends in a given community, using repeated cross-sectional surveys to assess a wide range of issues such as injuries, respiratory health problems, post-traumatic stress, emotional and financial stress, depressive symptoms, excessive drinking, psychosocial support received, sense of community belonging and so on, among a random sample of the local population.

Disaster-related losses should be measured in order to be able to examine health outcomes as a function of the level of exposure to the disaster. Various types of losses can be considered, including human losses (such as loss of a loved one, fear for one's life or that of a loved one, suffering injuries), material losses (such as home damage, permanent or temporary relocation, job loss), and subjective losses (such as perception that the event was stressful, that something important was lost, that something important was interrupted, or that harm will potentially occur in future).

Such surveys are powerful tools for health promotion initiatives and local advocacy initiatives. They help with raising awareness, providing an understanding of the full scope of local issues, as well as understanding the preferences and needs of the community to inform priority setting. By doing so, they contribute to the tailoring of interventions aiming to support citizens, communities, and inter-sectoral partners, and, more generally speaking, to the promotion of resilience and recovery processes *(7)*.

Beyond traditional surveys and other quantitative methods, qualitative approaches (such as focus groups and interviews) are also valuable for ensuring that the voices of groups who are disproportionately at high-risk are heard, in order that their specific needs and capacities are taken into account (see Chapters 4.12 and 4.13). It is important to take time to listen and learn from citizens, and to consider all members of the community as assets rather than victims *(2)*.

Regardless of the extent of the problems observed in the field, public health must seek a balance between a deficit-approach, which focuses on needs as well as disease or ill-health, and an asset-approach focused on strengths, capacities and resources of the community *(8)*. A good understanding and mastery of these two approaches is necessary for teams working in a psychosocial recovery context.

### 3.1.4 Asset Mapping

Bortel and colleagues *(21)* describe an asset approach to health as one which "...aims to identify those health-promoting or protective factors operating at different levels ... within individuals, communities, organizations and systems that are most likely to lead to higher degrees of overall health, well-being, achievement and sustainability". Asset mapping, which complements an asset approach, is a method that originated in the field of community development and is used to identify outcome measures that are asset-oriented *(22–23)*. Asset mapping was introduced by Kretzmann and McKnight in the early 1990s to promote citizen engagement and empowerment, by creating opportunities for participation *(22–24)*. It is based on a strengths-based approach to challenge traditional deficit-oriented mapping that has been employed in development initiatives. This method focuses on identifying resources that promote health and resilience in a community or organization, in contrast to deficit-oriented mapping, which has a pathogenic orientation to identify what makes people ill *(25)*. A balanced approach is needed if people are to be empowered *(11)*.

In the past decade, asset mapping has gained recognition as an upstream strategy for DRR (such as the CART Community Resilience Toolkit *(26)*, the EnRiCH Community Resilience Intervention *(2)*), and more recently for use in the recovery phase *(27)*. There is better understanding of the need to engage communities in identifying not only physical resources that can support resilience, but also social assets across multiple ecological levels (such as person, interpersonal, institutional, community, broader society).

The asset model for public health proposed by Morgan and Ziglio *(11)* describes asset mapping as an assessment method for intervention design. In support of this, Tracey and colleagues *(28)* developed a list of asset indicators that can be used for asset mapping to build organizational resilience. They used one-on-one interviews and focus groups to consult with representatives from essential service organizations. Thematic analysis was used to identify emergent themes related to organizational resilience from this qualitative dataset. The themes were then used to develop asset-oriented indicators which can be used by organizations to measure adaptive capacity within organizations to support disaster resilience.

For Health EDRM research, a diverse set of assets should be considered in pre- and post-disaster contexts. One of the challenges in asset mapping is to define and categorize different types of assets; both Hobfoll *(29)* and Moser and Satterthwaite *(30)* developed categories to address this challenge. The categories of assets span socioecological levels. They include individual, household, institutional, community and societal levels. Table 3.1.1 shows four types of asset categories that can be used for asset mapping. This list was created by combining the categories identified by Hobfoll *(29)* and Moser and Satterthwaite *(30)* for the purpose of household asset mapping with families impacted by stroke *(31)*.

**Table 3.1.1 Sample of Asset Categories *(31)***

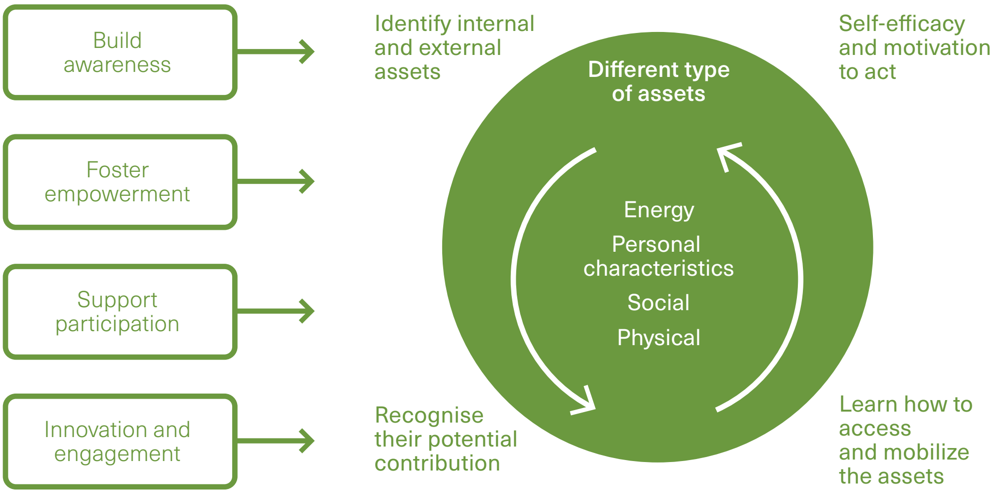
| Asset Category | Description (and examples) |
|---|---|
| **Social** | Assets that involve people, community networks, social programmes, and are related to the social environment (such as family, friends, neighbours, culture, informal communication channels, social services, policy, bylaws). |
| **Personal Characteristics** | Assets within a person that can be mobilized to support resilience (such as knowledge, skills, attitude, perseverance, creativity). |
| **Energy** | Energy assets are those which can be converted into other assets to support prevention/mitigation, preparedness, response and recovery (such as money, time invested by an organization or group). |
| **Physical** | Tangible assets in the physical environment that support needs and operational functioning of different systems in the community (such as power grids, roads, housing, water treatment systems, transportation). |

### 3.1.5 Asset Literacy

Literacy is a common term used to refer to learning and cognitive processing around different domains. The UN Educational Scientific and Cultural Organization (UNESCO) defines literacy as “the ability to identify, understand, interpret, create, communicate and compute, using printed and written materials associated with varying contexts… Literacy involves a continuum of learning in enabling individuals to achieve their goals, to develop their knowledge and potential, and to participate fully in their community and wider society” *(32)*.

Asset literacy, a type of literacy, can be improved through asset mapping and stakeholder consultation. This concept was developed through a series of studies in which the processes and outcomes of asset mapping were observed and discussed *(4, 28, 31)*. Basic asset literacy is being able to identify assets which can then be categorized according to the types described in Table 3.1.1. For utility, however, awareness must be fostered so that people and organizations understand the potential value and contribution of different types of assets to support resilience. Beyond this awareness is empowerment, where citizens understand how to mobilize different assets in their communities and how to get involved to contribute their own assets to support their communities. Opportunities for social participation (such as through stakeholder engagement) is key for asset literacy to expand to this actionable level. Finally, innovation and engagement are supported when people have self-efficacy and motivation to act on their knowledge of assets. Self-efficacy is similar to confidence, but includes perceptions of control *(33)*. O’Sullivan and colleagues *(31)* expand on this description of asset literacy in a research study with stroke survivors who described assets they would rely on to support resilience in a disaster (Figure 3.1.1).

**Figure 3.1.1 Components of Asset Literacy *(31)***



## 3.1.6 Stakeholder Engagement

Citizen engagement is central to the relevance and success of asset mapping interventions. It is critical to acknowledge stakeholders when identifying acceptable and effective solutions, taking into account evolving needs and the local context *(22, 26)*. Formally, stakeholder engagement refers to the active and equitable involvement of a diverse group of stakeholders, including the community, opinion leaders and media, in the research process *(34–35)*. Its purpose is to enhance the relevance of research to policy and practice, increase the transparency of the process, and reduce the time between knowledge generation and adoption into practice *(34)*. Engagement of the affected community can also contribute to the broadening of outcome measures by identifying assets within the community which can shape the research agenda and public health initiatives. It is not a trivial endeavour, but one that requires the time and commitment of researchers and decision-makers to redistribute power among all those involved, enabling communities to contribute their expertise and gain a shared sense of ownership *(36–37)*.

The tradition of involving stakeholders is evident in several academic research approaches, including community-based participatory research *(35, 38)*, participatory action research *(39)*, implementation science *(40)* and knowledge translation *(41)*. Although not new, stakeholder engagement is increasingly recognized as important by research funding organizations and many research initiatives. To effectively engage stakeholders in research projects, the research team must first identify the relevant stakeholders, broker relationships, collaboratively define roles and meaningful engagement activities. Any of these steps may be revisited throughout the research process to adapt and adjust to emergent needs of the stakeholders or community. The steps are outlined below.

Firstly, it is important to engage stakeholders and communities early in the process, so as to incorporate their ideas into the research questions while the study protocol is still malleable. To help identify relevant stakeholders, Concannon and colleagues *(42)* developed the 7P framework which includes:

i) patients and the public;

ii) providers;

iii) purchasers;

iv) payers;

v) policy makers;

vi) product makers; and

vii) principal investigators.

Although this framework was developed for health services research, the categories are applicable to Health EDRM. For example, "providers" could refer to professionals in health care (such as nurses, physicians, paramedics and so on), emergency services (such as fire, police, ambulance), or emergency management (incident commander, for example). Another way to conceptualize stakeholders is at the micro (individual), meso (organizational), and macro (policy) level *(43)*. The goal is to bring together stakeholders with diverse backgrounds, expertise, and skills relevant to the area of inquiry. Oftentimes, stakeholders are identified within a research team's first- and second-degree network connections, meaning relationships are already established. In cases where the identified stakeholder is unfamiliar, the research team can reach out to the individual to introduce themselves and invite them to the table. This strategy of cold contacting requires time and patience to broker a meaningful relationship.

Once stakeholders are invited to the table, there are several considerations that must be made around the design of the research project. This requires, and is not limited to, planning the roles of stakeholders, recognizing the values and objectives of engagement, and scheduling activities to exchange information *(34, 37)*. Phillipson and colleagues *(44)* noted several ways stakeholders have contributed to projects, such as providing input on study design, participating as research participants, supporting data collection, providing resources (such as facilities and materials), giving feedback, and helping to disseminate findings. Consultation methods, such as the structured interview matrix (SIM) facilitation technique, are also effective for garnering feedback from stakeholders and stimulating solution-oriented thinking across different sectors in the community *(2)*. Other activities used to engage stakeholders include town halls, small group meetings, establishing a community of practice, lunch and learns, and online collaborative platforms, to name a few. The key is to ensure that stakeholder input is reflected in the research study, and that decision-making power is a shared responsibility so that engagement moves beyond symbolic partnership but becomes one that is active and mutually beneficial.

### 3.1.7 Applying an Asset Lens to Outcome Measurement

To redress the balance of a deficit-based approach, an asset lens can be applied to assess the strengths and capabilities of a community *(24)*. Outcome measurement is not only important for assessing the negative impacts to a community, but also emergent strengths and capacities *(11)*. Using a socioecological model can help to differentiate which level the strengths or assets reside in: individual, organizational, and community or society. Rippon and South *(45)* conducted a rapid review of the literature for the WHO to determine how asset-based approaches are being used in the field of health promotion and public health for intervention design and evaluation.

There is a need for better identification of what makes a community resilient, through an assessment of assets before, during and after emergency or disaster (that is, its characteristics, strengths, and resources) that are associated with greater community resilience *(26)*. Local knowledge should be considered in the same manner as scientific knowledge. Having been through a unique and informative experience, the local health workforce involved in psychosocial management can benefit from drawing and sharing lessons in the aftermath of a disaster.

Case study research has a strong foothold among academics and practitioners as a methodology for studying disasters, due to its emphasis on providing in-depth and comprehensive information about an event. Case studies can therefore be used to capture the experiences of communities preparing for or impacted by disasters, and further illuminate assets that bolster resilience. To fully realize the potential of this type of methodology, standard formats, which include both deficit- and asset-based outcome measures, are needed to guide case study reporting. This would facilitate the pooling and sharing of such local evidence. In time, these case studies could be subjected to meta-analyses, to distil common features that transcend each unique emergency or disaster ravaged community. Some guidelines for these types of case study might include sharing lessons about:

- the needs and assets in the local community
- how and by whom these needs and assets should be addressed
- barriers and success factors for sustaining resilience and recovery.

### 3.1.8 Conclusions

Given the context of disaster prevention, preparedness, response and recovery, it is natural to focus on risks, hazards and vulnerability. However, adoption of an asset-oriented lens can stimulate innovation and solution-oriented thinking to complement an all-hazards approach in Health EDRM. Asset mapping requires investment and commitment by leaders to support grass-roots initiatives that foster citizen engagement. This type of initiative is the essence of an all-of-society approach to disaster health research, but it requires meaningful opportunities for participation by all.

### 3.1.9 Key messages

- **A balanced paradigm which recognizes both assets and risks is needed to support better outcome measurement in disaster research.**
- **Stakeholder engagement must be part of asset mapping to ensure broad community perspectives and that local context is included in assessment and measurement.**
- **Asset mapping can inform outcome measurement, but it is important that indicators reflect a balanced paradigm by including appropriate measures that consider assets in a community.**
- **Asset literacy is both a process and an outcome measure, which emphasizes local knowledge and intervention strategies that support community participation.**

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# 3.2

# Disaster risk factors – hazards, exposure and vulnerability

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## 3.2.1 Learning objectives

To understand the key factors to consider when developing a study to assess risk factors relevant to health emergency and disaster risk management (Health EDRM), including:

1. How hazards, exposure, and vulnerability/capacity create disaster risk.
2. The unique challenges of defining, identifying and measuring risk in disaster research.
3. Common issues of validity and quality in causal research in disasters.
4. How to conduct a study to assess disaster risk factors.

## 3.2.2 Introduction

In disasters, there are three broad areas of risk to health: the hazard that can cause damage, exposure to the hazard and the vulnerability of the exposed population (see also Chapters 1.3 and 2.5) *(1)*. Disaster research often strives to show that these risks affect morbidity, mortality or well-being in some way. This provides evidence to inform decisions relevant to Health EDRM.

Causative studies look for a risk factor that, if removed, would prevent the associated adverse outcome. A hypothesis is developed to explain the relationship between exposure to the risk factor and the outcome, and assumptions are made about what other factors (usually called confounding factors) might influence the relationship. The conclusions that can be drawn depend on how well these elements are addressed and measured when conducting the study and interpreting the results.

Research on disasters requires critical reflection around choosing and measuring risk factors because of the pragmatic difficulties inherent with conducting research in disaster settings *(2)*. This chapter outlines areas of disaster risk and discuss how research can be used to determine the causes of the problem, and how these causes and the size of their effects can be measured reliably. Chapter 4.2 provides additional information on how to undertake and interpret the statistical analyses that would help with this.

### 3.2.3 Hazards

Disasters often follow a hazard that negatively impacts a population *(3)*. Hazards can take many forms:

**Natural: earthquake, landslide, tsunami, cyclones, extreme temperatures, floods, or droughts**

**Biological: disease outbreaks including human, animal, and plant epidemics and pandemics**

**Technological: chemical and radiological agent release, explosions, and transport and infrastructure failures**

**Societal: conflict, stampedes, acts of terrorism, migration, and humanitarian emergencies**

Many ways to classify hazards exist (see Table 3.2.1 for an example). Hazards can occur individually, sequentially or in combination with each other. A primary hazard can be followed by secondary hazards, as seen with the earthquake, tsunami, and radiological hazards in the 2011 East Japan disaster (Chapter 1.3) *(4–5)*. Timing, severity, geographic location, and frequency are important characteristics of hazards. Hazards can have a short or long duration, and can have different impacts depending on the time of day, week or month when they happen *(6)*. They can be sudden onset, like an avalanche, or develop slowly over time as the result of a combination of factors. Deforestation, for example, is a slow onset hazard which can stem from factors such as limited resource management, land use planning, economic opportunities, and climate change. Hazards can be severe in their scope and impact or small-scale and localized. Hazards can happen infrequently, like radiological incidents, or frequently, like hurricanes and typhoons. How important these characteristics are and how they are translated to risk is relative to the population exposed to the hazard. For example, areas of the southern USA frequently experience hurricanes of varying strengths. People living in mobile homes in these regions are more likely to evacuate their homes during a hurricane because they perceive their risks to be high, based on prior experience with hurricanes and the strength of the hurricane, compared to those who live in more strongly built structures *(7)*.

### Table 3.2.1 Truncated WHO Classification of Hazards *(8)*

| Groups | Sub-groups | Examples of main types |
|---|---|---|
| **Natural** | Geophysical | Earthquake, geophysically triggered mass movement, volcanic activity |
| | Hydrological | Flood, wave action, hydrometeorological triggered mass movement |
| | Meteorological | Storms, extreme temperature |
| | Climatological | Drought, wildfire, glacial lake outburst |
| | Biological | Air-, water-, and vector-borne diseases, animal and plant diseases, food-borne outbreaks, antimicrobial resistant microorganisms |
| | Extraterrestrial | Impact, space weather |
| **Human-induced** | Technological | Industrial hazard, structural collapse, fire, air pollution, infrastructure disruption, cybersecurity, hazardous materials (including radiological), food contamination |
| | Societal | Armed conflict, civil unrest, financial crisis, terrorism, chemical, biological, radiological, nuclear, and explosive weapons |
| **Environmental** | Environmental degradation | Erosion, deforestation, salinization, sea level rise, desertification, wetland loss/ degradation, glacier retreat/melting |

Case Study 3.2.1 describes the interaction of hazards with risks, using the example of earthquakes and masonry in Nepal.

### Case Study 3.2.1
### Structural risks during a hazard: Earthquakes and low-strength masonry in Nepal

Low-strength masonry of stone or bricks with mud mortar is the dominant building typology in Nepal and has been used as a building material since ancient times. It is still used in many parts of the country. Construction of early monuments, temples and residential buildings was generally limited to materials that were readily available and easily worked by local artisans. The trend at present is to use cement-based construction, especially in urbanizing areas.

In April 2015, an earthquake and its aftershocks killed more than 8800 people and injured more than 22 000, largely due to the damage to low-strength masonry structures. Among other factors, the impact on life depended on building vulnerability and the evolution of construction methods. Indeed, fatalities from the earthquake indicated that, on average, there had been a reduction in building vulnerability in urban areas, whereas buildings in rural areas remained highly vulnerable. A post-disaster needs assessment reported the following damage to houses associated with masonry strength *(9)*:

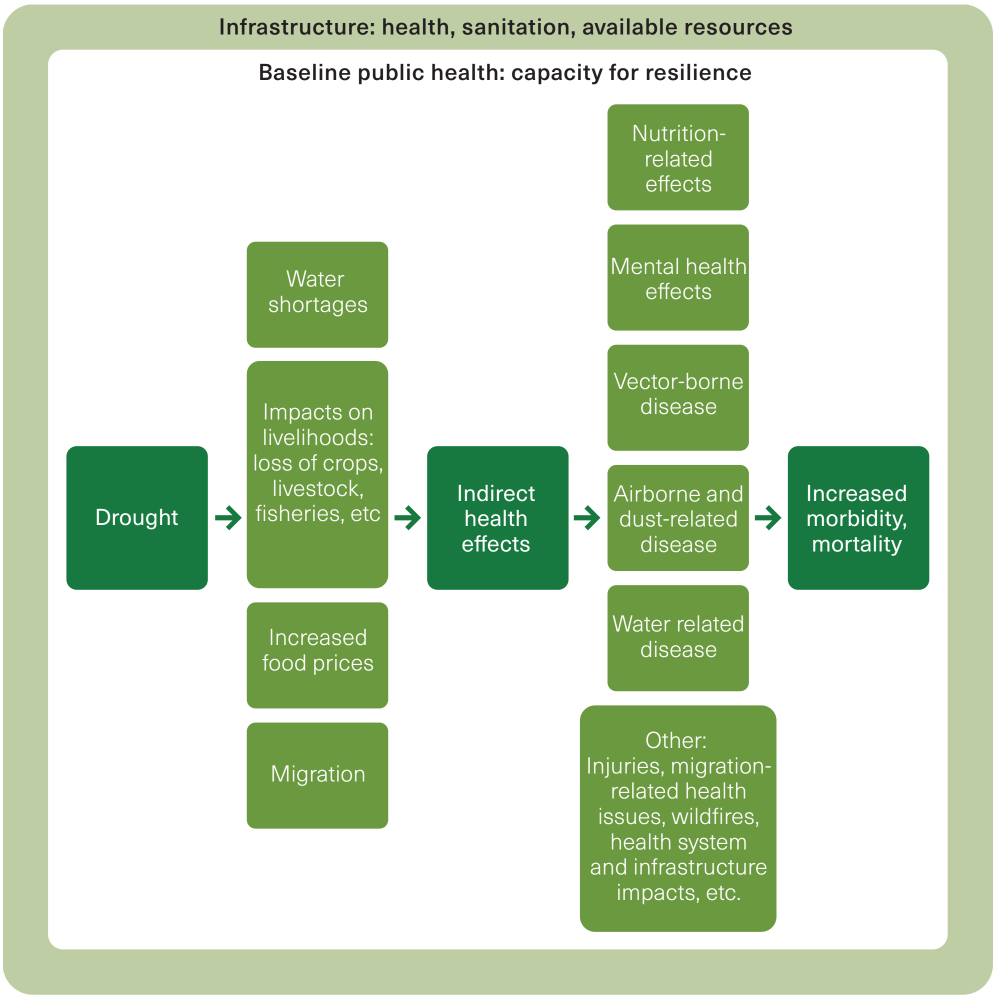
| | Low-strength masonry | Cement masonry | Reinforced concrete | Total |
|---|---|---|---|---|
| **Partially damaged** | 173 867 | 65 859 | 16 971 | 256 697 |
| **Fully damaged** | 474 025 | 18 214 | 6 613 | 498 852 |

The National Society for Earthquake Technology in Nepal started conducting training on earthquake resistant construction of vernacular buildings for masons in the late 1990s, and the government has taken the lead with national and international support, especially after the 2015 earthquake. There remains a continuing need for the institutionalization of a comprehensive, multi-tier and hands-on training certification programme to teach further skills in improving seismic performance of buildings and for developing nationwide capacities in earthquake-resistant reconstruction.

## 3.2.4 Exposure

Populations and societies need to be exposed to a hazard to be affected by it. Populations are often talked about as being directly or indirectly affected. Direct effects include injury, illness, other health effects, evacuation and displacement, and economic, social, cultural, and environmental damages. Indirect effects refer to additional consequences over time that cause unsafe or unhealthy conditions from economic, infrastructure, social, or health and psychological disruptions and changes. One of the major challenges in disaster research is measuring who has been affected and when. Determining which effects can be attributed to a disaster is complex, as there are multiple indirect pathways to an outcome (Figure 3.2.1). This is further complicated when populations are repeatedly or continuously exposed to a hazard, and when the time until the effects appear varies. For instance, disruptions to the health system and persistent stress from exposure to a hazard can lead to a greater burden of chronic conditions that may not present until months or years after a disaster.

**Figure 3.2.1 Example of the indirect impact of droughts on health *(10)***



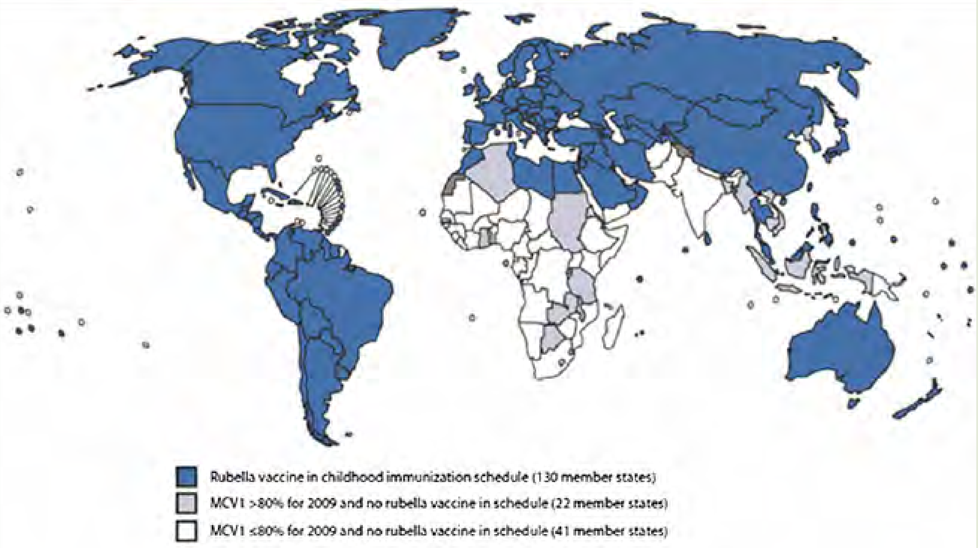
Case Study 3.2.2 shows how exposure risk can be reduced by changes to organizational behaviour.

### Case Study 3.2.2
### Changing organizational behaviour to reduce exposure risk: Vaccination to prevent congenital rubella syndrome

In the first half of the twentieth century, the link between infectious diseases and birth defects was not known. Rubella was a common childhood infectious disease, but also occurred in adults, including pregnant women. It was not until 1941 that the ophthalmologist Norman Gregg noticed that there were more infants with congenital eye problems that year than in the preceding years, and realized that their mothers had had rubella when pregnant. By reviewing patient records, he connected the increased number of infants with congenital eye problems he had observed to a large epidemic of rubella which had recently occurred, and went on to show that rubella in early pregnancy could be linked to many serious birth defects in children. The possibility that an apparently trivial illness could cause major birth defects like deafness, blindness, and heart defects was initially dismissed, and it took time for the association to be understood and identified as congenital rubella syndrome *(11)*.

Recognizing the value of vaccination to reduce exposure risk, the number of WHO Member States using rubella vaccines in their national immunization programmes continues to grow, increasing from 83 out of 190 Member States in 1996 to 130 out of 194 in 2009 (Figure 3.2.2). As a result, rubella has been eliminated in the WHO Region of the Americas to less than 1 case of congenital rubella syndrome per 100 000 births. Developing comprehensive vaccination programmes to prevent exposure to rubella required high-level political commitment and partnerships, proven technical strategies and surveillance tools, ongoing training for surveillance staff, and recognizing outstanding performance by individual countries. *(12)*

**Figure 3.2.2 Countries using rubella vaccine and countries meeting WHO criteria for rubella vaccination introduction, 2009**



### 3.2.5 Vulnerability

Vulnerability and capacity are made up of a wide range of physical, social, economic, and environmental factors, and are closely tied to development *(13)*. Vulnerability is highly dependent on the context of the hazard, since it is shaped by the context's individual factors and behaviours, history, politics, culture, geography, institutions, and natural processes. This can include things such as land use, public infrastructure, the burden of disease in the population and previous exposure to hazards. What makes people vulnerable is complex, and vulnerability can be both a risk factor for and an outcome of disasters. Vulnerability is discussed in Chapter 2.5 in relation to high-risk groups but, for example, poverty can put people at risk by forcing them to live in areas highly exposed to hazards, and exposure to hazards can cause poverty by damaging assets, interrupting livelihoods, and so on. While some factors can make an entire population vulnerable, such as poor governance or corruption, others are individual or specific to certain groups. Examples include level of education, social mobility, access to economic resources, physical and mental capacity, language barriers, or formal access to protection and services (see Case Study 3.2.3). As discussed in Chapter 2.5, some groups that are commonly thought of as having higher levels of vulnerability are *(14)*:

- People living in poverty
- Women
- Children and youth
- Older people
- People with disabilities
- People with chronic illness or underlying health conditions
- Migrants
- Ethnic minorities and indigenous peoples
- Sexual minorities

### Case Study 3.2.3
### Understanding individual vulnerability as health risk: Cold weather impacts and the social determinants of health *(15,16).*

The health risks and impacts resulting from cold weather greatly affect the most vulnerable people in society, such as children, older people and the chronically ill. Cold temperatures increase the risk of respiratory infections, stroke, heart attack and hypothermia, for example. Most countries affected by the impacts of cold weather have developed and implement each winter a 'cold weather plan' to help institutions and individuals better prepare and respond to cold temperatures (example: Cold Weather Plan for England *(17)*). Preventing cold-related illnesses and deaths is possible but requires interventions to reduce vulnerability.

In order to understand how this could be done, a mixed methods study (Chapter 4.13) using surveys and interviews with older people was conducted in Lisbon, the Portuguese Republic. The study found that the following factors are associated with vulnerability and the ability to adapt to cold weather: health status; knowing what to do during cold weather; individual awareness of vulnerability; quality of housing; costs of heating (electricity and gas); social networks; medical support; and health costs. These results provide evidence to inform policy and practice on opportunities for reducing the vulnerability of older people to cold weather. These include life-long education, knowledge sharing and learning, individualized advice by health professionals on what to do during cold weather, financial incentives to improve home insulation, subsidies to reduce the costs of heating, and improving social safety nets and activities for older people. An example of such interventions exists in the United Kingdom through the 'Keep Warm, Keep Well' initiative *(18)*. This provides financial incentives to help reduce the costs of keeping warm at home for those who cannot afford it. Other innovative policy and practice interventions are needed to assist and support individuals in reducing their vulnerability to cold weather

### 3.2.6 Determining and measuring risk factors

All causative studies are prone to issues around validity. Internal validity is the extent to which an individual study can answer the research question. In classic experimental research, such as a randomized trial (Chapter 4.1) the hypothesized causal factor can be manipulated to see what effect it has on the outcome (such as testing the efficacy of different dosages of a drug). Although the cause-and-effect relationship can be affected by confounding factors that are associated with the exposure and the outcome, a well-designed study will identify potential confounders and control for them. A good study will also try to reduce its selection bias and choose a study population so that the exposed and unexposed group do not differ in ways that can affect the outcome.

Typical experimental methods are difficult or impossible to apply when studying risk factors, because doing so would require the researcher to expose the population to hazards that might be harmful to them. Furthermore, in disasters, the study population and exposed group are often ‘selected’ by the disaster itself, depending on the geographic location of the hazard, biologic agent and route of transmission involved, and so on. Researchers are then left with the task of identifying a control group to which the exposed group can be compared, in order to see what effect the risk factor – rather than any other element – had on the outcomes of these people. Common examples are to compare the same population before and after the disaster, or to compare groups in highly affected versus less affected geographic areas. Researchers need to be keenly aware of the potential differences in risk between these groups. For example, someone studying floods and social support may select people living in a flood plain as their affected group and people living in a nearby mountainous area as their comparison group. In this case, consider how the hazard will affect each region; a larger proportion of displacement because of mudslides in the mountainous region compared to the flood plain may be a key difference between the groups that could affect social support *(19)*.

Researchers who use data collected for other reasons (often called “secondary data”) (Chapter 4.4) need to think about who is missing from the data. Data that comes only from medical facilities, for instance, will not include people who were unable to access healthcare, and this population may differ substantially in health status or socioeconomic status from those who were able to do so. An example of this is an unexpected reduction in mortality after flooding that was observed in a health dataset from the United Kingdom *(20)*. The reduction may have been the result of the affected population moving away and dying in geographic locations that had not flooded and were thus not reported as dead in the dataset from the flooded area.

Identifying which risk factors to use in a study will depend on the context and outcome *(21)*. Factors must have a logical link to the outcome to be a risk. One way to help determine this is by using a source-pathway-receptor approach *(22)*. A factor (the source) may be a risk if there is a reasonable pathway for it to cause harm to a population (receptor), and if the harm in the population can be traced back to the factor. This has been used to evaluate flood risks *(23)*, where the river is the source, the floodplain is the pathway, and the people living in the floodplain are the receptor. The impact on the people living in the floodplain can be traced back to the river that flooded via the floodplain. Using risk assessments are another approach that can help to identify the relevant hazards, direct and indirect exposures, and potential vulnerabilities of interest for the context *(14)*.

Measuring risk factors requires a firm understanding of the relationship that will be assessed. A study interested in the relationship between a hazard and an outcome will need to choose which characteristics of the hazard and population are relevant for their hypothesis. Using the example of hurricane exposure and PTSD, it would be necessary to decide if it is important to study ethnicity and level of exposure to the hurricane, or if individual trauma is expected to have the same impact on the outcome as neighbourhood trauma *(24)*. Any assumptions the researcher makes about relevance need to be explicitly stated. This is a helpful way to keep the study focused, avoid introducing bias, and guide the search for information.

Careful consideration also needs to be given to how to measure a risk factor. Some risk factors, such as age, can be measured directly. Others, like social exclusion, are more open to interpretation by the researcher and study population. Directly asking a study population is one way to measure risk, but accurately and completely recalling information, events, or situations from before, during, and after a disaster is challenging, and the information received from the participants can be inaccurate and biased. For any data that are collected, the tools used to measure risk should be tested and piloted in a similar population before data collection begins. A good measurement will be reliable, and produce similar results among similar participants. Pre-validated tools do exist for certain domains, especially for psychological research *(25)*, but attention should be paid to how well the questions and concepts translate from the context where the tool was developed to the context where it will be used, and it is important to keep in mind that all factors can be measured and defined in multiple ways. This raises issues about comparability of findings among research studies that use different definitions and measurements. A good rule of thumb is to clearly state the definitions and measurements that are used in the study, and the rationale for choosing them.

External validity is the extent to which the results of a study can be applied to other situations. Thinking about external validity means acknowledging the selection bias in the study and how this may affect the results, and understanding the study setting so that the findings can be interpreted in a realistic way. This is particularly important for disaster research, when the unique combinations of hazards, exposure, and vulnerability means studies are conducted in a specific context that may not be replicable elsewhere. While a single study may have poor external validity, it is still part of a larger base of evidence that can help people to understand the relationship between a risk factor and outcome *(26)*.

### 3.2.7 Conclusions

Health EDRM requires a good understanding of the risk factors that, when coupled with hazards relevant to a disaster, can cause health problems and harms. Research into this needs to take account of the interaction between hazards, exposure, and vulnerability or capacity. Then, when this research is being considered by decision makers, they need to assess the study's internal validity (relating to how well it was conducted) and external validity (relating to its relevance to settings or times other than where and when the study was done).

### 3.2.8 Key messages

- **Disasters are a combination of hazards, exposure and vulnerability. Finding causative factors for disaster outcomes means examining risk factors in these areas.**
- **Risk factors can combine in unpredictable ways, creating a complex and unique research context. While it can be difficult, this complexity must be grasped and acknowledged if research is to be valid.**
- **When designing, conducting and using research, careful scrutiny of the definitions, measurements, and risk factors used is important to understand what conclusions can be drawn from the individual study and from the overall body of evidence.**

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# 3.3

# Designing a research intervention for Health EDRM

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## 3.3.1 Learning objectives

To understand important factors to consider when designing an intervention for health emergency and disaster risk management (Health EDRM), including:

1. Key social and behavioural science theories, models and framework that could be used for designing interventions for the management of health risk arising from an emergency or disaster and related evaluative research.
2. Theory-derived intervention methods.
3. Methods to use for planning and developing an intervention to achieve behavioural change.

## 3.3.2 Introduction

A health intervention is an act or set of actions performed for, with, or on behalf of a person or population with the objective of assessing, improving, maintaining, promoting or modifying health functioning or health conditions. A wide array of approaches exists for designing and researching interventions for the health risks associated with disasters and emergencies, and this chapter discusses some of these in the context of Health EDRM.

Although the focus has long been on relief responses during and after the onset of the disasters, Health EDRM now emphasizes interventions to be applied throughout the disaster management cycle, starting with prevention and mitigation of health risks through to empowerment of communities and national capacities to provide timely and effective response and recovery. Prevention occurs at three levels: primary, secondary and tertiary. Primary prevention involves either preventing the hazard from occurring or preventing exposures to the hazard leading to injuries or diseases. Secondary prevention involves interventions such as early diagnosis and management of injuries or diseases after the exposure has occurred. Tertiary prevention attempts to avoid further complications leading to more severe injuries, disabilities or death. Interventions aiming at changes in the determinants of health behaviours and environmental conditions during the pre-impact phase help build resilience of individuals and communities to risks, as well as their capacities to respond to and recover from the effects of emergency and disasters.

This chapter is intended to provide a framework for intervention development that can guide healthcare practitioners and policymakers involved in designing and researching effective interventions. It begins with the planning phase, which includes needs assessment, and outlines the dominant theories or models  for explaining and changing behaviours and environmental settings that can be used to inform the intervention methods.

### 3.3.3 Needs and resources assessment

Needs and resources assessment is a prerequisite for understanding the targeted populations, the risks they face and the available resources (such as people, time, budget and political will) that will help inform the design of any intervention. Assessment involves the researchers' collection of epidemiological, social, environmental and health service information that could describe the existing situation (see also Chapter 3.1). During this stage, researchers responsible for designing an intervention also need to determine the prevalence and incidence of the problem as a whole and among sub-populations, as well as identify audiences of the health intervention in order to achieve maximum outcomes (Chapters 2.1 to 2.4).

The PRECEDE-PROCEED model *(1)* provides a useful example for this. The PRECEDE part of the model provides a framework for understanding the causation of health problems at multiple levels and the consideration of multiple determinants of health-related behaviour and social and physical environment. Phases 1 to 4 of PRECEDE explain the various perspectives to be assessed:

**Phase 1: Social assessment:** determine the problems and needs of a targeted population and identify desired results.

**Phase 2: Epidemiological, behavioural and environmental assessment**: identify the health determinants of the identified problems and set priorities and goals.

**Phase 3: Ecological assessment**: analyse behavioural and environmental determinants that predispose, reinforce and enable the behaviours and lifestyles.

**Phase 4: Administrative and policy assessment:** identify administrative and policy factors that influence implementation and choose appropriate interventions that lead to desired and expected changes.

The targeted populations and stakeholders should be involved in all aspects of the PRECEDE model. They may suggest issues that need to be analysed in detail. Despite the importance of primary data, secondary data from reports or studies conducted by other agencies should also be examined.

### 3.3.4 Understanding theory and approach

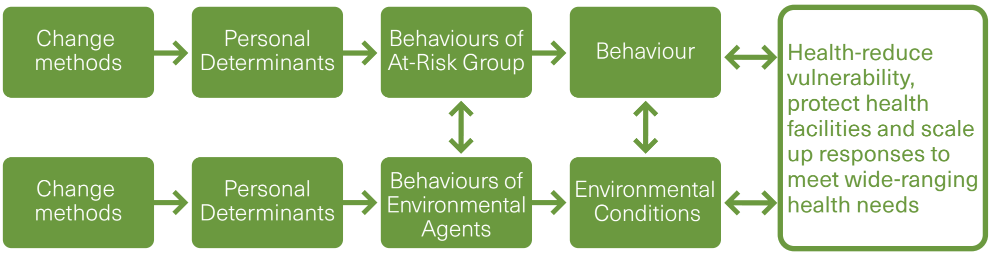
Improving the implementation of Health EDRM practices depends on achieving changes in behaviours and environmental settings. The prevention and control of communicable and noncommunicable diseases, as well as climate change-induced risks, require behavioural change. Deaths, injuries, diseases, disabilities, psychosocial problems and other health impacts brought about by emergencies and disasters could be reduced or avoided through effective interventions that initiate, promote and sustain behavioural changes at individual, interpersonal and community levels.

Behaviour change interventions are implemented to change behaviours that are associated or causally linked to mortality and morbidity. They are designed based on behaviour change theories or models, which are a combination of approaches, methods and strategies drawn from social and health sciences, such as psychology. Behaviour change theories guide an understanding of people's behaviours as individuals or groups (interpersonal, organizational, community and societal) and play a critical role during the various stages of an intervention, such as when identifying what information is required to develop an intervention strategy that will be effective *(2)*. Systematic reviews have indicated that using behavioural theory or models in the selection, planning, implementation and evaluation of interventions can lead to more positive effects than interventions designed without the support of any theory or model *(3)*.

Although a multitude of health behaviour theories or models for the development of interventions exist, criticisms prevail about the lack of research into the choice of theories *(4)* and the description of interventions *(5)*. This chapter therefore discusses some of the most widely used theories or models for understanding behavioural changes, including the kinds of changes needed to enhance emergency and disaster risk management *(6)*.

Human behaviours happen in a complex ecological system. A health problem could therefore be understood in an ecological way (Figure 3.3.1), which includes behavioural and environmental determinants, for making an informed choice as to the levels of intervention *(7)*. Changing health behaviours involves altering an individual's attitude and motivation, which may be influenced by a range of people (such as family members, teachers and colleagues) and conveyed in a variety of settings (such as home, school and workplace). The settings enable the interaction of the environmental, organizational and personal factors to affect health and well-being *(8)*.

**Figure 3.3.1 Logic Model for Methods, Determinants, Behaviours, Environmental Conditions and Health *(7)***



## 3.3.5 The health belief model

The health belief model *(9–12)* is among the most popular conceptual frameworks in health behaviour research and provides a guide to frame interventions to change health behaviour (Table 3.3.1). The health belief model provides a useful, simple, actionable model and is commonly used for prevention and detection (such as vaccination against influenza, injury prevention and hazard preparedness) *(6, 13–15)*. However, its efficacy, effectiveness and impact remain limited.

Therefore, many researchers have extended the original health belief model or identified other variables to be incorporated into it, which could enhance its predictive capacity – to such an extent that the model no longer only comprises the key constructs *(16)*. Moreover, for most effective use, the health belief model should be integrated with other models that account for the environmental context and suggest strategies for change *(17–18)*.

**Table 3.3.1 Key constructs and definitions of the health belief model *(9-12)***

| Construct | Definition | Application |
|---|---|---|
| Perceived susceptibility | Belief about the probability of experiencing a risk or suffering from a disease | Identify populations at risk and assess their risk levels;<br>Define the risk based on an individual's characteristics, behaviour or experience. |
| Perceived severity | Belief about how serious the situation is and its consequences | Specify the consequences, which could be multi-dimensional (such as physical illness, mental health deterioration and relationship issues). |
| Perceived benefits | Belief in the potential benefits of the action | Define the action to be taken (such as what, where, when and how).<br>Describe the positive effects. |
| Perceived barriers | Belief about the potential barriers carrying out the action | Identify and tackle the barriers such as costs, loss of opportunities through reassurance, incentive, etc. |
| Cues to action | Strategies to activate behaviour change | Provide information and reminders. |
| Self-efficacy | Confidence in the ability to take action | Training and guidance to strengthen one's confidence in taking the recommended action.<br>Goal setting and reinforcement. |

### 3.3.6 Theories of reasoned action

Although theories of reasoned action do not suggest methods for changing health behaviours, theories of reasoned action have their significance in understanding health risk behaviours among people who are aware of the negative outcomes associated with behaviour. These started with the Theory of Reasoned Action (*19*), then the Theory of Planned Behaviour *(20)*. Later, these authors co-developed the Reasoned Action Approach *(21–22)*. While the Theory of Planned Behaviour emphasizes that behaviour intention is determined by some conceptually independent elements, such as one's attitude towards the behaviour, subjective norm and perceived behaviour control, the Reasoned Action Approach includes subcomponents of attitude (experiential/instrumental), perceived norm (injunctive/descriptive) and perceived behavioural control (capacity/autonomy) as well as environmental constraints to predict intention and behaviour *(23)*. The Theory of Planned Behaviour provides a useful, multi-factorial, actionable model, but empirically its prediction for actual behaviours, beyond the mere intention, has remained modest – and especially so for generic and complex behaviours. The SMART specifications required to achieve high prediction can become ludicrously precise. The Theory of Planned Behaviour remains a good model for articulating the cognitive factors (beliefs and knowledge) with the social pressure and the enabling environment (control, competencies, skills, power and so on).

These theories of reasoned action have captured the belief and the intention to change. The stronger the intention to engage in behaviour, the more likely it is that it will be performed. In previous studies, the Theory of Planned Behaviour has predicted an individual's intention to engage in certain behaviours, such as the use of helmets while cycling, the prevention of sexually transmitted diseases through human papilloma virus (HPV) vaccination and adaptation or mitigation of climate change *(24–26)*. The Reasoned Action Approach has also been applied in multiple contexts, such as smoking cessation, HIV prevention, health promotion and changing multiple behaviours *(27)*.

### 3.3.7 Stage theories: The transtheoretical or stages of change model

Stage theories suggest that people in different stages require different methods to help them cope with the stage they are in, and so finally change *(28)*. The transtheoretical model (the stages of change model) *(29)* is not a direct behaviour change theory but rather a time perspective on the deployment of behaviour change development and unrolling. It reveals that behaviour change unfolds through a series of stages *(30)*.

The transtheoretical model focuses on the decision-making of the individual and is a model of change. It assumes behaviour change does not happen quickly and decisively, but rather that the process of change occurs continuously and can relapse at any time. Unlike other theories or models where behavioural change is regarded as an individual event, the transtheoretical model postulates that such change is a process that needs to progress through a series of five stages for behavioural change (Figure 3.3.2 and Table 3.3.2). The stages include pre-contemplation,

contemplation, preparation, action and maintenance. For each stage of change, different intervention strategies will be applied to move the person to the subsequent stage of change until they reach the maintenance stage to accomplish the behavioural change.

**Figure 3.3.2 The Transtheoretical Model and Stages of Change *(28-30)***

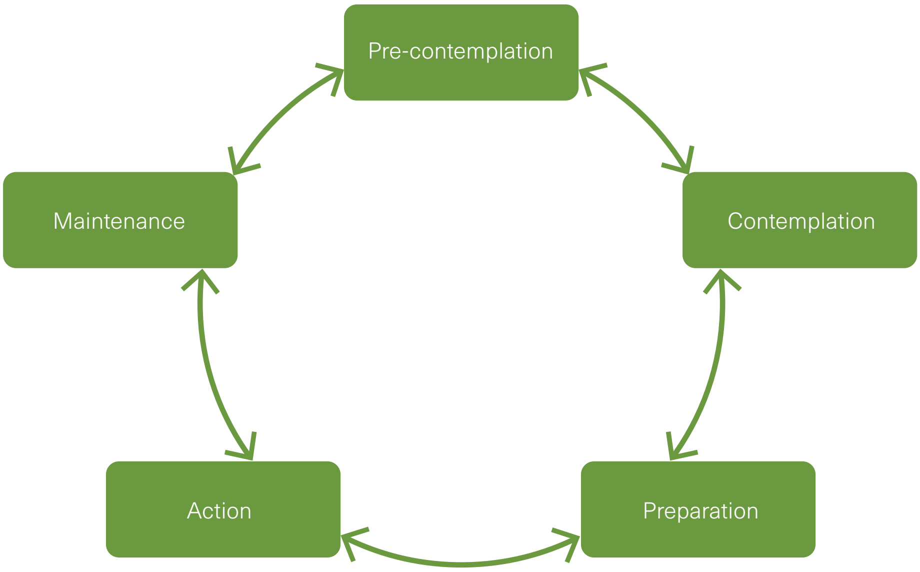


**Table 3.3.2 Stages of Change in the Transtheoretical Model *(28-30)***

| Stage | Description | Intervention Strategy |
|---|---|---|
| **Pre-contemplation** | Do not intend to take any action in the near term, usually within six months | Raise the awareness of the need for change; personalize the information about risks and benefits. |
| **Contemplation** | Be thinking about the behavioural change, but has not made a commitment to take action | Motivate the individual, encourage or support them to make action plans. |
| **Preparation** | Is prepared to take action within 30 days and has taken some preliminary steps | Help the individual to develop a specific, measurable action plan as well as goals. |
| **Action** | Have made significant modifications in lifestyle over the past six months | Provide them with feedback, support and reinforcement. |
| **Maintenance** | Behavioural change has lasted for at least six months; individual is working to maintain the change and prevent relapse | Give them reminders to avoid relapse. |

The majority of transtheoretical model-related interventions focus on cessation of addictive behaviours and there is ongoing debate as to the validity of the transtheoretical model, such as its negligence of independent variables *(31)*. Some have also commented that effective longer-term health promotion requires longer-lasting interventions that may need to go beyond health education and incorporate environmental change strategies *(32)*. In view of these concerns, the precaution adoption process model *(33)* is also worthy of consideration for Health EDRM interventions and research, such as infection control and hazard risk management. The precaution adoption process model identifies seven stages along the path from lack of awareness to action and tailors potential designs of individual and organizational-level interventions throughout the process *(34)*. It raises consciousness among individuals and the community, specifies consequences of the risk and uses step-by-step process to provide information of those risks.

### 3.3.8 Social cognitive theory

Social cognitive theory is an interpersonal theory which proposes that learning happens in a context that is dynamic and with reciprocal interaction of the person, environment and behaviour *(35)*. The behaviours of an individual are influenced by their experiences and by observing the actions of people around them, taking into account the benefits of those actions. Reciprocally, the people themselves also exert influence on their surroundings. Social cognitive theory interventions are based on active learning that promotes performance during the entire process composed of the following six constructs:

i) Reciprocal determinism: the core concept of social cognitive theory, the dynamic and reciprocal interaction of person, environment and behaviour.

ii) Behaviour capability: an individual's ability to behave through necessary knowledge and skills, as well as knowing what to do and how to do it.

iii) Observational learning: individual observes a behaviour conducted by others and then replicates those actions.

iv) Reinforcements: the internal and external response to a person's behaviour. It will affect the likelihood of continuing or discontinuing the behaviour. Internal reinforcement refers to self-reward; external reinforcement refers to whether the environment encourages or discourages the enforcement of the behaviour.

v) Expectations or anticipated outcomes of the behaviour: one anticipates the outcomes before adopting the behaviour and this influences the successful completion of the behaviour.

vi) Self-efficacy: the level of one's self-knowledge or confidence that one can succeed in adopting the behaviour.

Social cognitive theory considers many determinants of the social ecological model *(36–37)* in explaining the behavioural change of individuals. Methods derived include modelling and reinforcement. It has been applied to behaviours that are complex and require much behaviour capacity, for instance, in the promotion of physical activity and disaster preparedness *(38)*.

### 3.3.9 The setting approach

Aside from theories or models informing interventions to promote behaviour changes, the setting approach, where setting is defined as “the place or social context in which people engage in daily activities in which environmental, organizational and personal factors interact to affect health and wellbeing”, was laid out in the 1986 Ottawa Charter for Health Promotion. This holistic and multifaceted approach has been developed into intervention programmes such as Healthy Cities (one of the most widely recognized examples of the settings approach), Safe Hospital Initiatives (*39*) as highlighted in the Sendai Framework *(40)*, and Health Promoting Schools. These highlight community participation and empowerment, inter-sectoral partnerships and participant equity for health promotion *(41)*.

While research on epidemiological and environmental risk transitions reveals that environmental risks might be responsible for 25% to 40% of the global burden of disease *(42)* (see also Chapter 2.3), the healthy environment or settings approach *(43)* have become prominent for health promotion. Meanwhile, in consideration of problems with the setting approach *(44–45)*, it has been “revitalized” with the advance to the supersetting approach. The supersetting approach is an ecological approach *(46)* emphasizing that health promotion interventions may be optimized through the integrated efforts of a variety of stakeholders such as private, public and voluntary sectors and civil society. The principles of integration, participation, empowerment, context-sensitive and knowledge-based development have guided the variety of stakeholders to carry out coordinated activities within the supersetting (school, hospital, home, workplace, and so on) to achieve a sustainable impact on community health promotion. Evidence has demonstrated that the supersetting approach is a useful conceptual framework for developing and implementing a complex multicomponent health promotion intervention. Still, more research on its sustainability may be required. For instance, “ownership” of the development and implementation of the activities has been identified as a motivational factor to foster sustainability of the intervention *(47)*.

In summary, the setting approach is a useful framework for developing intervention-based initiatives or enhancing the effectiveness of interventions. It emphasizes that coordinated and integrated health promotion activities that are implemented together with multiple stakeholders and across multiple settings are powerful in bringing about change. Similarly, in the promotion of individual and interpersonal behavioural change, a single theory could not explain all aspects or determinants of a health problem. A multi-theories approach should always be adopted when designing or tailoring interventions.

### 3.3.10 Techniques employed in intervention designs

The following techniques can be employed to design interventions that could resolve a health problem. Again, there is no single method dominating intervention development and intervention research. The various methods could be applied in combination and with consideration to feasibility, efficacy and cost:

- **Chunking:** this enhances the performance of memorizing and learning outcomes, facilitating comprehension and fluency by using thought units *(48).*
- **Cues:** these are a technique to retrieve information. The use of cue reminders may increase the effectiveness of interventions that aim to prevent health-risk behaviours *(49)* especially when presented at the time of encoding and retrieval. For instance, by printing the oral rehydration solution formula on a teaspoon, it reinforces the behaviour of making and using the solution when having diarrhoea.
- **Elaboration:** unlike chunking, elaboration is for an audience with the ability to process the information and are motivated to do so. Techniques to effective elaboration include rehearsal such as disaster preparedness drills, where more information could be gathered and consolidated among the audience.
- **Fear:** arousal of fear has long been used as a method to raise awareness of risk behaviour and promote change *(50).* However, it only motivates individuals who have high outcome and self-efficacy expectations. Fear has been adopted in NCD prevention and intervention.
- **Nudging:** these interventions are broadly defined as a rearrangement of a choice context that gently suggests a specific choice, with some applications in domains such as health *(51).* Further research in nudging is needed to help improve understanding of applied nudging interventions *(52).*
- **Social marketing:** this is a behavioural change approach that adapts commercial marketing techniques to achieve specific behavioural goals for a social good. Research shows that despite its small effect by clinical standards, it can have a large impact on population health *(53).*

Among the different types of intervention that might be used, researchers and practitioners should examine the effectiveness and feasibility of each before finalizing their choice. Furthermore, an approach of multiple interventions targeting different layers of stakeholders (such as the general public, patients, practitioners, regulators and decision-makers) might prove more effective *(54)*.

The effectiveness of an intervention refers to how well it reduces the burden of a disease (Chapter 2.3), as well as its efficacy and cost. This may require knowledge of the epidemiology of the disease *(55)*. In disasters or emergency situations where infectious diseases can be life-threatening, interventions have to be effective at multiple points in the chain of transmission (that is between the vector, the host and the environment). Cost is important not just for healthcare practitioners but for researchers too. The intervention must be provided within the budget allocated. Moreover, although primary prevention is always the most cost-effective prevention level, for policy-makers, prevention is not always sufficiently visible and palpable, with the result that rescue or curative actions might be more attractive and perceived to be more impactful. Convincingly documenting the gains from prevention intervention is critical. Lastly, the effectiveness of an intervention also depends on the cultural and social beliefs of the audience.

Feasibility describes how easy it is to implement the intervention and its related research. Complex interventions are more challenging to implement *(56)*. The feasibility of an intervention depends not just on organizational factors, but also on gender, cultural and political factors *(55)*. There should be an assessment of how acceptable the intervention is to the community and its stakeholders. Researchers may need to consider whether the intervention requires a high degree of community involvement and whether the expected outcome is possible.

Table 3.3.3 presents examples of intervention strategies that can be used in relation to Health EDRM; Case Studies 3.3.1, 3.3.2 and 3.3.3 provide detailed descriptions of interventions to prevent influenza and Ebola virus disease, as well as for disaster prevention and preparedness.

### Table 3.3.3 Examples of Health EDRM intervention strategies for emergencies and crises

| Health risk related to health emergency and disaster | Topical focus | Strategies or interventions used |
|---|---|---|
| **Epidemic** | Interventions to combat a cholera outbreak. | WASH intervention techniques *(57)*<br>Modelling: Reinforcing cholera intervention through prediction-aided prevention *(58)* |
| **Pandemic** | Interventions to be used during 2009 A/ H1N1 influenza pandemic. | Use of antiviral drugs together with social distancing (such as extended school closure) may substantially slow the rate of influenza epidemic development in the initial stage *(59)*.<br>Risk communication strategies used during the pandemic included "speaking with one voice", involving academic experts and government officials in the effort, and targeting core groups of at-risk populations. Activities included awareness campaigns, advocacy, call centres, online response capacity and multi-ministerial, nongovernmental and private sector partnerships *(60)*. |
| **Dead body management** | Interventions for safe and dignified burials after disasters or during outbreaks of infectious disease. | Policy or guidelines enforcing the better management of dead bodies have been released, including "Management of dead bodies after disasters: A field manual for first responders" which provides practical and easy-to-follow guidelines on the recovery, documentation and storage of the remains of individuals who have died in disasters *(61)*. Another WHO guideline outlines the steps for the safe and dignified management of patients who have died from suspected or confirmed Ebola virus disease *(62)*. These guidelines have helped promote community engagement, awareness raising on the contagious Ebola virus disease as well as respect towards the cultural practices and beliefs (Case Study 3.3.2). |
| **Basic sanitation** | Health education and communication strategies to reduce faecal-oral transmission of disease and exposure to disease-bearing vectors. | Awareness raising and adoption of practices in personal or household hygiene such as handwashing, improved water and sanitation through health education and demonstration of health practices such as handwashing have been achieved (Case Study 3.3.3). |

**Case Study 3.3.1**
**Non-pharmaceutical interventions for the prevention of pandemic influenza**

An influenza pandemic is an ever-looming threat. Non-pharmaceutical interventions, also known as community mitigation strategies, are a critical tool as the first line of defence for limiting the transmission and spread of influenza. Non-pharmaceutical interventions demonstrate the ecological approach to health promotion. They include personal and interpersonal levels of prevention such as better handwashing *(63)*, the use of facemasks and covering the mouth when coughing. Most interventions have been done at the community level, such as introducing checklists stating specific actions to help public health professionals and administrators of schools, workplaces and mass gatherings for the implementation of non-pharmaceutical interventions *(64-65)*. These checklists address the concerns or issues from the “planning”, “take action” to “follow-up” phases for administrators of various settings to tackle. It should be noted that workplace emergency planning efforts occur with a recognition of, and in concert with, other levels mentioned in the ecological model, especially at the level of families and schools (such as working parents struggling to send their sick children to schools *(66)*).

Since the 2009 influenza pandemic, several countries have geared non-pharmaceutical interventions into their national influenza pandemic preparedness plans and there have been an increasing number of studies assessing the effectiveness of non-pharmaceutical interventions *(67)*. Furthermore, the importance of educating policymakers about the benefits of promoting an effective national influenza prevention and control strategies has been further reiterated. The WHO Global Influenza Strategy 2019-2030 *(68)* also highlights the expansion of seasonal influenza prevention and control policies and programmes using non-pharmaceutical interventions.

### Case Study 3.3.2

### Importance of health interventions for coping with the highly contagious Ebola virus disease in the Republic of Côte d'Ivoire

The 2014-2016 Ebola virus disease outbreak in West Africa was one of the largest Ebola outbreaks in history. It was first reported in March 2014 and officially declared over by WHO on 10 June 2016. The impact this epidemic had in West Africa, particularly in the Republic of Guinea, the Republic of Sierra Leone, and the Republic of Liberia is significant. Despite its proximity to these three countries, no cases had been reported in Cote d'Ivoire *(69)*.

A series of interventions were carried out in Côte d'Ivoire to prevent the spread of Ebola virus disease. First, a team of community health workers, community leaders and religious leaders was formed, which played a crucial role in delivering information about risks associated with Ebola virus disease. The Ebola-related health risks were also disseminated through major mass communication channels, such as television. Citizens who recalled thinking Ebola was a rumour during the initial disease outbreak later perceived the susceptibility to and the severity of the disease through news updates on the television.

Ebola virus disease is highly contagious. The priority in infection control is to avoid physical contact with the sick or deceased person, including their body fluids and the objects they have used. This highlights the challenge of dead body management. WHO, in partnership with the International Federation of Red Cross and Red Crescent Societies and faith-based organizations, developed a protocol outlining the step-by-step processes for safe and dignified burials *(62)*. The protocol highlights the consideration of cultural practices and inclusion of family in the planning, preparation and implementation of the burial, especially for Christians and Muslims, who have different burial rituals and constituted the majority of the populations being affected.

The Government of Côte d'Ivoire also implemented other prevention measures. It banned bush meat and promoted regular handwashing. It was suggested that people should raise their arms as a way of greeting instead of hugging and shaking hands. These interventions have been effective in controlling the transmission of the disease *(70)*.

### Case Study 3.3.3
### Health education intervention in a rural Chinese, earthquake-prone transitional village

CCOUC conducted disaster preparedness interventions, including face-to-face health education in 2009 and 2011, and an intervention evaluation research in 2018, in the earthquake- and flood-prone Dai and Yi ethnic minority-based community in Sichuan Province, China *(71)*. These interventions examined how the villagers' experiences and beliefs interact with the external social context (environment) to make certain behavioural changes. The research showed that awareness raising and adoption of practices in personal or household hygiene, such as handwashing, food and nutrition, and water and sanitation were retained. This suggests that the interventions not only improved the immediate knowledge of the participants, but also achieved temporal stability, as observed in 2018, seven years after the original intervention. However, the intervention to promote preparation of a disaster preparedness kit was found to be unsustainable because villagers' intention to prepare a disaster preparedness kit decreased over time.

Conceptualizing disaster preparedness as a social cognitive process may contribute to understanding of the improvement in the uptake of related health behaviours. The social context such as the improvement in socioeconomic conditions, the increased access to media and internet technologies as well as the knowledge transfer from the migrant populations may have contributed to the positive intervention outcomes. It should be noted that disaster response is regarded in China as a Government-initiated and organized activity rather than a personal or family-related responsibility *(72)*. This may explain the low intention of action. Meanwhile, the active promotion of disaster preparedness kit preparation through a bottom-up approach should be reinforced, with repeated educational efforts to enhance the improvement of self-efficacy in case of emergency.

### 3.3.11 Conclusions

This Chapter has discussed theories, models and settings to help researchers understand and review health problems, and so design effective interventions and related evaluations. One of the biggest challenges for researchers is to conduct translational research in which the knowledge gained from research is applied in the implementation of interventions that address critical needs and risks. The classical approach to translation of basic research findings into interventions typically takes some time (73) and further investigations are needed to shorten this time lag (74-75). This would improve identification, evaluation and implementation of effective interventions in Health EDRM, and improve the outcomes of the research in the long-run.

### 3.3.12 Key messages

- **Developing effective interventions in Health EDRM requires review of the most relevant and applicable theories or models, as well as understanding of relevant approaches.**
- **The theories on which the intervention design is to be based should be chosen on the basis of the health risk or problem as well as an understanding of the targeted populations and their health risk factors.**
- **Changeable factors and the mechanism for change should be identified.**
- **Translational research is needed to show sufficient evidence of effectiveness to justify implementing the intervention.**

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# 3.4

# Ethics in Research

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## 3.4.1 Learning objectives

To understand the following key concepts in research ethics as they apply to health emergency and disaster risk management (Health EDRM):

1. The role and importance of ethical considerations throughout the different phases of a research process.
2. The limitations of normative ethical guidelines when operationalized in emergency and disaster contexts.
3. The importance of reciprocal community engagement in ensuring valid and valuable results.
4. The role of project managers, research funders, national governments and research ethics committees.

## 3.4.2 Introduction

Emergencies and disasters significantly impact people's health and livelihoods. Whereas the health sector has traditionally focused on emergency response, Health EDRM shifts risk management to a more all-encompassing, proactive approach that emphasizes prevention and mitigation, alongside preparedness, response and recovery, across multiple hazards and reducing vulnerability through building community capacity *(1)*.

Decisions and priorities in Health EDRM in both programmes and research must involve ethical considerations that minimize short and long-term harm in a transparent manner *(2)*. Ethical guidelines are not simply obligatory approval mechanisms but are tools to promote more equal researcher-participant partnerships and uphold integrity throughout a project's life-course, from research design, review, implementation to publication *(3-4)*, in a way that protects and respects the community's welfare *(5)*. Ethical guidelines take into consideration the value of undertaking the project itself, assessing its contribution to social good, potential to save lives and reduce suffering, and the significance of knowledge outcomes. The consequences of failing to ensure ethical considerations are addressed can lead to problems of moral significance, such as loss of public trust, disruption of livelihoods, confusion about roles and responsibilities, and low morale of both researchers and participants *(6)*.

### 3.4.3 Limitations of normative ethical guidance

There is an ethical imperative to collect good data in all research. In Health EDRM, such data are essential to provide public health and clinical practitioners with high quality evidence on which to assess the impact of a crisis, identify necessary risk management measures and plan for future interventions *(7)*. Appropriate research findings are often lacking in the field of Health EDRM as many interventions are not evaluated in rigorous trials that result in evidence of adequate depth and quality *(3, 8)*.

Emergencies create unique challenges in logistics, security, resources and time-management *(9)*. Standard processes and procedures designed to operate in non-emergency circumstances may not be sufficiently flexible to adapt to the uncertainty inherent to disasters. However, changes to process or methodology can be perceived as undermining ethical rigour *(8, 10)*. Lower income countries are disproportionately impacted by disasters since technical capacity, governance and resources may be both limited and poorly coordinated, putting further strain on research implementation *(6)*. Other areas where there may be particular pressures during disasters that are not well addressed in normative guidance include: determining a fair approach to research participation; duties and roles at the interface between research, treatment and public health; management of expectations on the front line; and protection of participants from stigmatization, discrimination and exclusion *(10)*.

Despite these challenges, there is consensus that stakeholders must prioritize the interests of communities involved (see also Chapter 2.7), many of whom are at their most vulnerable during and after emergencies and disasters *(5)*. Pressures in time and situation should be assessed in the overall context and should not be excuses for bypassing the underpinning ethical values that ensure research is rigorous and fit for purpose *(7)*. Case Study 3.4.1, and the rest of this chapter, identify ways in which these values can be upheld despite the challenges to the procedures through which they are operationalized in non-disaster situations. These include the creation of specialist scrutiny committees and a strong focus on partnership working – to the extent possible – with affected communities.

**Case Study 3.4.1**
**Deviation from normative procedure: use of unregistered interventions for Ebola in West Africa *(11)***

During the 2014 West Africa Ebola outbreak, the rapidly rising case fatality rate under a fragile health system prompted calls to accelerate the development of interventions that were successful in laboratory and animal models, but had not yet been evaluated for safety and efficacy in humans. A WHO expert panel considered the ethical implications of using promising unregistered interventions outside the context of standard clinical trials *(11)*. The panel concluded that although this was a departure from well-established systems of regulation, it was acceptable on ethical and evidential grounds to offer the experimental interventions in the absence of any existing effective interventions, and under these unprecedented, exceptional circumstances *(12)*. Relevant ethical considerations both in the initial decision and in subsequent requirements for implementation included:

- The need to prioritize essential public health measures and resources
- Transparency to participants about the status of medical products and their uncertainty
- Transparency on risks and benefits
- Informed consent and freedom of choice, emphasizing the preservation of dignity
- Fair distribution of products in the event of scarcity
- Community involvement
- Full capacity by the research team to monitor and manage any side-effects and progress of treatment.

The panel also stressed the moral obligation of researchers to rapidly and transparently share all relevant data with the scientific community. Researchers have a moral duty to continue the evaluation of these interventions in clinical trials (see Chapter 4.1), in order to establish the safety and efficacy of the interventions for both current and future benefit *(11)*.

## 3.4.4 Value, feasibility and validity

The need to justify research in communities during or after emergencies is intensified In the light of the constraints described above. Decisions about research must take into consideration value, feasibility and validity:

**Value:** Identifying the necessity and added value of the proposed research is essential in justifying access to the available financial, human and time resources. It is therefore crucial for the research design to consider unmet needs of the target community *(3)*.

**Feasibility:** Feasibility and purpose, not just desirability, should steer research design. This includes: considering whether research should be done immediately after a disaster, or at a later point; the method and duration of data collection; or whether the research question needs to be adapted *(3, 13, 14)*. Importantly, research should be conducted in ways that are compatible with the existing healthcare response and public health needs *(15)*.

**Validity:** Unreliable or unusable findings can interfere with good practice and take up necessary resources during times of need. Reviewers have sometimes found that Health EDRM research lacks reliability and validity, which undermines its contribution to establishing baselines, standards, or trends *(7, 16)*.

It is critical to explicitly acknowledge any limitation. Researchers should also consider the risk of not undertaking research, or of prioritizing one project over another. Ultimately, researchers must consider the benefit of a project along with the cost of a missed opportunity.

### 3.4.5 Participant selection and exclusion

Research participation must be determined fairly, equitably and in line with objectives – and not due to privilege, access, perceived vulnerability or other subjective factors. Any exclusions should be based on valid scientific justification *(3)*. Those who are at particular risk of exclusion include those marginalized due to their age, gender, ethnicity, pregnancy, or previous trauma. Furthermore, damage to geographical, physical or governmental structures during emergencies could become barriers to access that result in research participation being decided on grounds of convenience rather than scientific validity *(7)*. Failure to include the necessary groups creates a knowledge gap in understanding the impact of an event across the entire population *(17)*. Exclusion can be particularly harmful in behavioural or mental health research (see also Chapter 5.1), as there is evidence that these marginalized groups experience significant long-term emotional and physical consequences following disaster events.

### 3.4.6 Informed consent

Informed consent is a process whereby potential research participants decide whether they wish to participate in a proposed study, having clearly understood the purpose and process of the research, including its risks and other implications. An informed consultative process has the potential to empower participants, build capacity, resilience and agency, and facilitate early identification of rights violations *(18)*. It is the researcher's duty to ensure that all necessary information has been communicated transparently, with consideration given to participants' health literacy, language barriers, and that decisions made by participants are well-informed, autonomous and voluntary.

While mainstream international guidelines unanimously agree that participant consent is mandatory, obtaining the appropriate informed consent can be practically challenging in Health EDRM. An individual's desire to survive may alter their perception of the potential harms of research participation. Researchers are often perceived as having the power to effect change, and it is crucial to be aware of power differentials and to not take advantage of potential participants' desperation and mistake this for voluntary and informed consent *(19-20)*. Populations in situations that render them particularly vulnerable, and who may lack clinical or research knowledge, are more likely to participate in research under the expectation of receiving assistance or monetary compensation without fully understanding underlying risks *(18)*. Although it cannot be assumed that all survivors of emergencies have impaired decision-making capacities, researchers should incorporate safeguards to ensure adapted procedures are used for particularly vulnerable groups in order to not exclude or exploit them based on any perceived vulnerability *(7, 21)*.

Innovative ways have been developed to improve informed consent. For example, members of the community can be involved within the research infrastructure so as to contribute local perspective, act as translators to inform potential participants, and become trained in research methods themselves *(3)*.

### 3.4.7 Harm-benefit

Health EDRM researchers operate in unstable contexts and so unforeseen obstacles will occur – the extent of which can range from inconvenience to participants, to psychological discomfort, loss of dignity or inflicting physical harm *(13, 21)*. In justifying the added value of research, any potential harm must also be considered, taking into account the novelty and necessity of the research *(20)*.

In practical terms, there is an ethical responsibility to structure research in a way that minimizes risk exposure by balancing risk with protective measures to alleviate burden and distress, particularly for participants who may be made more vulnerable by their age, gender, ethnicity, disability or previous trauma. Community representatives could be recruited as advisers in the planning process, to ensure researchers have an understanding of potentially controversial topics, such as those involving gender roles, family dynamics, political beliefs, and abuse. International researchers in particular must be cognisant of how their presence and behaviour may be perceived by the community *(3, 20)*.

In addition, researchers must consider risks to themselves and ensure they do not cause additional burden in settings facing geographic, political or medical instability *(22)*. Potential harm can be mitigated through training in cultural awareness, psychological support, security and practical protection measures. Research supervisors and funders are responsible for delaying projects until risks decrease, should this be necessary, and for not placing front-line researchers into high-risk settings without appropriate protection *(3, 20)*.

### 3.4.8 Participant protection

Research can be intrusive, so it is necessary to protect participants' interests while maintaining methodological rigour, particularly where vulnerability is exacerbated. To the extent possible, participants should be viewed as 'collaborators' and never just as 'data' *(23)*. At the same time, researchers must be alert to the potential power differentials, and associated risks of misunderstanding and exploitation. Welfare, privacy, confidentiality, protection from stigmatization and respect to gender, religion and culture must be acknowledged, regardless of urgency *(3)*. In order to be able to recognize what might constitute "harm" or "stigmatization" within a population, community involvement during the study development phase is crucial, especially where international researchers are involved. A breach in trust, or reinforcing stigmatizing factors, can result in harm to participants or wider communities, and in compromising the research, can in turn impact public health outcomes *(7)*.

To protect both participants and their information, researchers should include the following operating procedures *(7, 24)*:

- Avoid exposing participants to further harm as a result of the research, including physical and psychological harm.
- Respect each participant's freedom to withdraw from research.
- Assist participants in understanding their rights and any potential risks in a manner they can understand. Consider involving local representatives in sharing necessary information between the participant and research groups, as community awareness can reduce anxiety and promote ownership.
- Do not collect information that is not related to the research activity and minimize the use of identifiable information, such as by using codes to refer to participants rather than names and addresses. Irrelevant data collection wastes resources, and adds a burden to data storage and protection (see also Chapter 4.4).
- Be explicit about the intended use of the information collected, and the circumstances under which it will be collected and shared.
- Securely store information and ensure access is limited. Physical data should be locked, and electronic data should be password protected and encrypted. Assign "record-keepers" within the research team to oversee data storage and sharing, which includes distribution method and to whom it is shared. Technological advances continue to shift the benchmark for what constitutes as secure, and it is important for those responsible for data management to keep up with such advancements.
- Fully consider the impact of publishing findings, including the consequences of not doing so, such as the reaction of national governments or other relevant authorities.

Case Study 3.4.2 provides an example of the importance of research participant engagement in conducting research relevant to Health EDRM.

### Case Study 3.4.2
### Research participant engagement during the 2006 Israeli-Hezbollah war in the Lebanese Republic

Research undertaken by the American University of Beirut sought to assess the psychosocial status and needs of the internally displaced people in order to inform appropriate psychosocial interventions in wars. In addition to methodological difficulties, such as security and access, the experience of the researchers illustrated how conducting surveys in wartime intensifies certain ethical considerations. Important considerations arising out the researchers' experience include:

- Different expected outcomes between researchers and participants. Some participants attempted to expand the research focus into issues that addressed other needs, which caused diversions during data collection, sometimes resulting in overt conflict that was not easily resolved. Researchers have an ethical duty to clarify expectations, even if this decreases the likelihood of participation. This experience further emphasizes the importance of prior community engagement in order to identity priority research needs.
- The scope for harm in asking participants to reflect on a traumatic experience. It is important to be sensitive to individuals' reactions in these discussions. While some may feel indifferent or feel relieved and unburdened, others may be negatively triggered. In this case, data collectors were asked to stop the survey at first sign of distress and shift to casual conversation.
- Approaching potential participants who may feel humiliated by their living conditions. Media images from the camps showed some of those living there covering their faces. Survey participants were given the opportunity to describe their pre-war living conditions, which many did with pride.
- Concern that communities felt obliged to participate in return for assistance or provision as it was political "gatekeepers" and welfare providers swho were linking students with participants. It is the responsibility of the researcher to ensure participants have freedom of participation, with no sanction resulting from refusal *(25)*.

## 3.4.9 Community engagement

Ethical integrity in research is rooted in mutually respectful partnerships between researcher and participants, which increases the likelihood of developing mutual trust, of local ownership of the research aims, and of generating results that are valuable to the community. Researchers should work to achieve relationships that are as reciprocal, collaborative and transparent as possible, where participants feel their needs and interests are acknowledged *(6)*. Time pressure during emergencies should not be an excuse for researchers failing to engage *(15)*.

Effective and respectful community engagement starts with recognition of the broader situation, experience and practice of the affected population, as these are factors essential to people's identity, dignity and reactions. This can include understanding: the successes and weaknesses of the local health system; the situation of staffing, structure and resources;

unmet needs; familial and community relationships; and culturally or politically sensitive subjects. Historically, emergencies have most impacted those with limited financial resources, education and knowledge about clinical research, so special measures should be taken to include representatives from all subgroups, including the most marginalized to the extent that is possible, in order for the research outcomes to reflect their needs and experience, and to generate useful, valid data *(15, 26)*.

For the research to be appropriate, for the community to understand the objectives, and for relevant harms and benefits to be identified, participants' communities must be consulted continuously in a two-way process throughout the design, implementation and reporting of research *(10, 14)*. This can be achieved through identifying key stakeholders, including political, military and religious leaders, local media, social influencers and women's organizations at the earliest opportunity. Information can be gathered through focus groups, surveys or interviews with diverse community representatives, and in turn shared by integrating and coordinating within existing services such as community health workers (*15*).

Some have suggested that by participating in relief efforts or volunteering within the community, researchers can build a rapport, and promote mutual understanding about the research goals *(27)*. However, this relationship can cause confusion in distinguishing researchers from responders, and blur the line between research and provision of care. Regardless of potential benefit to participants, the purpose of research is to achieve scientific goals and contribute to knowledge, and the potential for therapeutic misconception must be acknowledged. This can include misinterpreting the benefits of an intervention or, conversely, downplaying harm. Some ethicists have even suggested that informed consent should include clarification on the differences between research and provision of care *(28)*.

It is important to not promise what cannot be delivered and to maintain a respectful relationship between researcher and participant. Furthermore, effective communication and feed-back mechanisms are essential for addressing rumours or misunderstandings, which are grounded in valid experiences and should not simply be dismissed. Communities must be able to receive information about research progress and outcomes in ways that are respectful of their contribution *(15)*.

### 3.4.10 Stakeholder roles and responsibilities

There are other important stakeholders in the research process, beyond the researchers themselves, who have responsibilities in ensuring a project is planned, designed, and implemented appropriately. These include research managers, research funders, national governments and research ethics committees, as outlined below. Other stakeholders also include civil society organizations, other local research facilitators, and members of the international community.

**Research managers**
Research managers should encourage needs-based collaboration, national ownership and sustainability of a project, which includes avoiding the "parachute" or "lone" researcher model. Managers are accountable for the safety and welfare of their front-line staff, and need to take appropriate action to manage both the inherent risks staff face in working in dangerous settings, and any additional risks associated with the research. Staff must also be provided with adequate guidance in identifying and managing practical ethical issues throughout the life-course of the project. This includes completing cultural sensitivity and security training in order to successfully work in complex settings, and ensuring access to ongoing support as needed. Local partners and staff can help international organizations interpret and respond to certain situations; however, these local staff must also be protected from unfair employment practices or mistreatment from their community as a result of being involved in research *(15, 29*).

**Research funders**
Research funders should be fully informed on resource and access constraints during emergencies and disasters before defining or prioritizing activities, in order to avoid unrealistic and subsequently unmet expectations. They should actively promote collaboration and encourage capacity development and community engagement in research projects. This can include providing resources to enable partnership with local entities or civil society organizations. Having a holistic view on projects, research funders should monitor potentially duplicative research in order to avoid unnecessary research burden on participants *(10, 13, 17)*.

**National governments**
National governments are responsible for strengthening their emergency preparedness under the International Health Regulations (2005). This includes overseeing and pushing forward the scientific agenda for coordinated, integrated, partnership-based research, in particular by supporting academic and research capacity strengthening for the development of national expertise. National governments also have a role in overseeing and coordinating research to ensure competing research priorities do not overburden the population. This is particularly important during emergencies, where the influx of multiple agencies may cause confusion over roles and mandates *(15)*.

**Research ethics committees**
Research ethics committees (see Chapter 6.4) are responsible for promoting high ethical standards, which include overseeing participant protection and accounting for potential risks *(30)*. Although there is agreement that the research ethics governance systems need to be timely and flexible in the context of Health EDRM, and that committees should have relevant technical capacity to assess these projects, there is little consensus about what this adapted process looks like in practice, and further work is needed in this area *(5, 10)*.

The final case study in this chapter, Case Study 3.4.3, provides another example of how high quality, ethically conducted research can lead to important findings for Health EDRM.

**Case Study 3.4.3**
**Delivering on the promise of research: Collaborating with the New York City Fire Department following the 9/11 terrorist attacks**

Past research has shown that people are more willing to participate in research if it is seen to benefit the health system, recovery efforts, or clinical services, rather than be purely experimental. This process relies heavily on trust. Populations affected by disasters have lived through a physically and mentally traumatic experience and may prioritize coping with the aftermath, rather than other activities.

The 2001 9/11 terrorist attacks on the World Trade Center in New York City resulted in 2735 deaths, including 343 firefighters and paramedics who died during the response, over 6000 injured, and countless suffering long term physical and mental health effects *(31)*.

Following 9/11, the New York City Fire Department published early assessments of cancer outcomes associated with the event, which affected federal health care policy, and was eventually translated into cancer being added to 9/11 insurance coverage. New York City Fire Department was also involved in various studies on short and long-term declining pulmonary function in responders. Blood banked following the aftermath of 9/11 has been used to link biomarkers to pulmonary function, potentially predicting susceptibility and resistance to the disease.

New York City Fire Department firefighters had agreed to participate in this research as long as they felt the outcomes were beneficial to themselves or another responder. Maintaining this trust was particularly important in allowing researchers to conduct successful longitudinal studies into the long-term health outcomes of 9/11 responders.

Researchers partnered with the American Cancer Society and the US Centers for Disease Control and Prevention (CDC) to secure buy-in within the community, and found that partnership with these credible organizations was beneficial to the success of the project *(32)*.

### 3.4.11 Conclusions

The goal of health research is to obtain knowledge that will improve health and healthcare and help refine future programmes. For Health EDRM in particular, balancing the pursuit of knowledge with ensuring the safety and wellbeing of participants can be challenging *(20)*.

Ultimately, successful outcomes are dependent on ethical practices throughout the entire life-course of a project, that ensure validity, accountability and sustainability. These are all built on mutual respect between researchers and the communities where the research takes place. It is important that scientific progress, ownership and capacity are retained through the appropriate inclusion of local institutions and communities, that evidence is published for future use, and that learnings are systematically fed back into the community so that they may build evidence-based resilience in the future *(15)*. Experience-sharing will promote robust ethical practices that prioritize participant protection within the complexities of Health EDRM research *(5, 10)*.

## 3.4.12 Key messages

- **There are ethical aspects to consider throughout the design, review, implementation and publication phases of research that go beyond merely obtaining ethical approval. These considerations help researchers to mitigate against any potential short- or long-term harm to stakeholders in a transparent manner. In addition to evaluating potential for harm alongside scope for immediate benefit, researchers must also take into account the potential broader impact of a project, for example its overall contribution to societal good, capacity to improve livelihoods, the adaptability of knowledge outcomes to benefit other research areas or communities and the potential harm of not filling an evidence gap with high quality research.**
- **Decisions about the design, implementation or use of research should take into account the value, feasibility and validity of the research question. The added value of research towards addressing an unmet need is necessary to justify the financial, time and human resources that is invested, including the value of missed opportunity in not conducting the research. The feasibility of implementing certain activities within a Health EDRM context must be considered alongside the desirability of completing a research project; and validity must be ensured to avoid unreliable or unusable findings.**
- **Normative ethical guidelines for research may have to be adapted when operationalized in emergency and disaster contexts due to the unique challenges faced across different areas including security, logistics, time-constraints, or availability of adequate human resources. However, there can be no excuses for bypassing the underpinning ethical or scientific values that ensure research is rigorous and fit for purpose.**
- **Reciprocal and continued engagement with the affected community is not only key to understanding practical and contextual elements that will facilitate the collection of data and improve the quality of evidence, but is also essential for the development of a respectful partnership in which the participants' interests are not only considered, but protected, especially within the Health EDRM context where the community is made more vulnerable by its circumstances. Outcomes of the research should ultimately be fed back to the community, in order to empower and build capacity, and promote resilience to future disaster or emergency situations.**

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# 3.5

# Determining the research question

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## 3.5.1 Learning objectives

To understand key factors to consider when determining the question that would be answered by research to resolve an uncertainty in health emergency and disaster risk management (Health EDRM), including:

1. Deciding on the general issue that needs to be studied.
2. Defining a precise research question for the study.
3. Confirming that the study is a priority, will make an important contribution to the existing evidence base and will not waste funding or other resources.

## 3.5.2 Introduction

The first step when planning, doing or using a research study to resolve an area of uncertainty in Health EDRM is to be clear about what type of information is needed. For example, the issue may relate to how often something happens, why it happens, how to change what would otherwise happen or what might happen when something new is done. The desire may be to try to explain what has already happened or to find ways to improve things in the future. Clarity in this helps, both in the development of the appropriate research question and in the choice of what type of study to use to answer it.

This chapter begins with an outline of some of the types of study that would be suitable for tackling the broad topics, which are discussed in more detail in other chapters. This is followed by a section on defining the research question and the need to ensure that answering this question is a priority and will not waste funding or resources.

### 3.5.3 Deciding on the broad topic

Research can generally be categorized as observational, in which the study looks at what has already happened or is likely to happen anyway in the future, or experimental, in which it investigates the effect of changing something. Taking the example of the Great East Japan Earthquake in March 2011 and subsequent problems at the Fukushima nuclear power plant *(1)*, observational research might study:

- the number and types of injury caused by the tsunami *(2);*
- the types of people most likely to suffer from subsequent PTSD, anxiety and depression *(3);*
- the consequences of evacuating people from the area near to the power plant *(4)*.

Experimental studies might be used to:

- investigate different ways of treating injuries *(5)* or preventing PTSD *(6);*
- identify effective and efficient methods for risk communication *(7)* and mass evacuation.

Furthermore, with events as rare as major radiological incidents *(8)*, such as Chernobyl and Fukushima, computer-based modelling studies might be used to predict the likely impact of policies such as "shelter in place".

Deciding on the broad topics that need to be studied allows choices to be made about the type of new research that would be most relevant. Observational studies investigate the consequences of certain events (see Chapters 2.2, 2.3 and 2.4) or risk factors (see Chapter 3.2), whereas experimental studies such as randomized trials (see Chapters 4.1 and 4.3) determine the effect of a new intervention, action or strategy and provide evidence to help people to decide whether it should be implemented in the future.

### 3.5.4 Defining the research question

For any new study, it is important that the research question is formulated correctly. It is the research question that will:

- underpin the choice as to which type of study to undertake;
- ensure that it is clear what is being investigated;
- ensure that the correct measurement tools are chosen;
- ensure any potential biases are avoided, such as those that might arise if the accumulating findings lead to unplanned changes;
- ensure that, if the study is completed successfully, it will provide a clear answer.

Case Study 3.5.1 provides an example of how a clear question produced a clear answer in an observational study in the aftermath of the Wenchuan earthquake in China in 2008.

### Case Study 3.5.1
### Analysis of inpatients and deaths in the West China Hospital of Sichuan University following the Wenchuan earthquake

The 8.0 magnitude earthquake that struck on 12 May 2008 affected nearly 46 million people and caused tremendous loss of life and property. The West China Hospital of Sichuan University is the only large-scale, state-level, general teaching hospital in the disaster area. It acted as the rescue centre for treating severe and complicated injuries caused by the earthquake, the support centre for the hospitals in the disaster area, and the logistics centre for medical teams from other provinces. It treated a total of 2728 injured people: 872 in the emergency department and 1856 admitted as inpatients. Amidst this delivery of health care, opportunities were taken to do research so as to provide evidence to help improve emergency plans for earthquakes and the establishment of state-level regional medical centres.

This research sought to answer questions such as “what were the gender, age, source, distribution of admission time, and types of injury of the patients?” And, “what were the causes of death among those who were admitted to hospital?” An observational study was designed to answer these questions, with clear definitions of what was to be counted and how. The findings were reported in the *Journal of Evidence-based Medicine* later that year *(9)*.

In the most straightforward type of experimental study, some participants are given the new intervention, while others act as a control group, continuing to receive the routine care. Many randomized trials use this simple, comparative design in which half the participants are randomly allocated to a new therapy and the other half receive usual care (see Chapter 4.1). The following paragraphs illustrate how the same basic topic for a piece of research would require different types of comparative study depending on the precise research question that is asked about the effects of the intervention.

The illustrative example is fish oil for treating PTSD, which was studied in a randomized trial after the Great East Japan Earthquake (see Case Study 4.1.1). If the broader topic is whether fish oil alleviates PTSD among people exposed to a disaster, there are many different possible comparisons that could be made, each answering a different research question, as discussed below.

#### Fish oil versus control

In this comparison, some participants would be allocated to take fish oil capsules and others would be asked to avoid them. In some studies, a placebo, or “dummy” capsule, might be given so that the participants and those looking after them or measuring their outcomes do not know who is receiving the fish oil. This simple design would answer the question “does taking fish oil have more or less benefit than not taking it?”. However, it will not show whether fish oil is better, worse or the same as taking a different therapy or using a different type of intervention.

**Fish oil versus another intervention**
If there is an acceptable alternative to the intervention being tested, comparing that intervention with no intervention is unlikely to help decision makers who are trying to choose between the intervention and an alternative they would routinely use. In this PTSD example, if routine practice is to provide counselling, then answering a question about fish oil versus no intervention is not helpful. Instead, a comparison of fish oil versus counselling would answer the question “does taking fish oil have more or less benefit than counselling?” However, it will not show whether fish oil might provide further benefit if it was given in addition to the counselling.

**Counselling plus fish oil versus counselling alone**
If counselling would be routinely used to prevent or treat PTSD, the previous comparison would investigate whether it might be worth replacing it with fish oil. However, people might be cautious about changing practice. To overcome this, a study would be needed in which everyone continues to be provided with counselling but some receive fish oil in addition. This would then answer the question “does fish oil bring any additional benefit to the normal management of PTSD?”

**Immediate fish oil versus delayed fish oil**
In some circumstances, the uncertainty might be about whether something should happen immediately or can be delayed. For example, the fish oil might be given straight away or delayed for a few weeks. During those few weeks, the measurement of PTSD would provide information that is the same as that from the first example above, when one group of people are receiving the fish oil and another group are avoiding it. However, after those first few weeks, both groups will have been given fish oil, just at different times. This design would show whether fish oil should be given immediately or later. However, it leaves some participants exposed to a no-intervention period before the delayed fish oil is given, and this might not be acceptable if an alternative, such as counselling, is available. This might raise ethical issues (see Chapters 3.4 and 6.4). In such a case, the comparison might need to become immediate fish oil versus counselling followed by fish oil, so that everyone is being offered something straight away.

There are even more possible permutations for this topic than the examples given above, including whether different sequences of fish oil and counselling have different effects, and the most appropriate dose or type of fish oil product. However, these examples illustrate how different research questions need different comparisons and so different types of study. They also show that if the research question is not carefully defined, the resulting study might not be of an appropriate design and so might fail to produce a meaningful answer.

People designing an experimental study need to decide whether to compare a new intervention, action or strategy against no intervention or against an alternative, or if the new intervention should be added to something that is already used. A study of the effects of a combination might also be used to investigate the sequence in which the components are given.

### 3.5.5 Avoiding research waste

Once a research question has been clearly defined, the researcher needs to be confident that the study will fill an important gap and ensure that it will not contribute to research waste *(10)*. In the context of Health EDRM, research waste could mean that doing the research actually does more harm than good by diverting resources that could be used for other purposes or by hampering the response and relief effort. It is important, therefore, to ensure that answering the research question is of sufficient priority to justify doing the study. Sometimes, working through the following steps leads to the research question being changed, in order to improve it and increase its relevance. One of the steps in determining this might be to do a scoping review (Chapter 3.6).

**Is the answer already out there?**
Before embarking on a new study, it is important to review the existing research to ensure that the research question has not been answered already. Reviewing the existing research might also help when designing the new study, by enabling researchers to draw on practical lessons learned from earlier studies *(11)*. Doing a systematic review (see Chapter 2.6) or finding one that has already been done by others (see Chapters 3.7 and 6.2) should help to clarify the topics to be investigated and determine the precise research question to answer. For example, Case Study 3.5.2 describes the Cochrane Review of the health effects of electric fans during heatwaves, which concluded with the suggestion for a randomized trial that would focus in particular on people living in nursing homes *(12)*.

#### Case Study 3.5.2
#### Health effects of electric fans during heatwaves

As heatwaves become more common, their devastating effects on health are likely to increase. For example, during the heatwave that occurred in Europe in August 2003, an additional 30 000 people may have died. People will often use electric fans to help them feel more comfortable as temperatures rise, and a systematic review *(12)* was prepared to provide evidence on their effects on health to help inform England's national heatwave plan in the run up to the London Olympics of 2012. This review found that the existing research was not able to confirm or refute the potential benefits and harms of using an electric fan during a heatwave. It highlighted a lack of reliable evidence on whether or not people with a fan were more or less likely to survive the heatwave. This is of concern because fans work by encouraging the evaporation of sweat, which can lead to dehydration, which can be particularly dangerous for vulnerable groups such as children and the elderly. When air temperatures are above 35 °C, it is postulated that the fan might actually contribute to heat gain by blowing hot air onto the body. The review highlighted that one way to resolve this uncertainty would be to conduct a new, high quality study and it proposed the following design for this:

**Population:** Adults of any age with or without co-morbidity who are likely to be representative of general population, with a particular focus on participants aged ≥65 years in residential or care homes; during a heatwave.

**Comparison:** Electric fan versus routine care.

**Outcomes**: Use of healthcare services, heat-related illnesses, deaths and self-report comfort.

**Design:** Randomized trial, possibly a cluster trial with randomization of specific settings (such as care homes) or areas (such as small geographic regions).

### 3.5.6 Is the research a priority?

Identifying priorities for research is challenging in any area, as discussed in Chapter 2.7. However, this is particularly true in Health EDRM where the range of evidence needed and the complexity of emergency response make it difficult to prioritize key questions that might provide the decision makers and those making choices about interventions, actions and strategies with the evidence they need. Case Study 3.5.3 describes a priority setting exercise which was led by Evidence Aid to identify a set of 30 questions used to prioritize the conducting or updating of systematic reviews *(13)*.

#### Case Study 3.5.3
#### Identifying the highest priority systematic reviews of humanitarian action

During 2011 to 2013, Evidence Aid worked with a group of partners on a priority setting exercise for systematic reviews, producing a priority list of research questions for new or updated systematic reviews. The process included contributions from representatives of, among others, Action Contre La Faim, ALNAP, Centers for Disease Control and Prevention (USA), Centre for Global Health Trinity College Dublin, Department for International Development (United Kingdom), International Federation of Red Cross and Red Crescent Societies, Médecins Sans Frontières (including the Epicentre-Paris), Merlin, Nutrition Works, Public Health England, Save the Children, UNICEF, UN Office for the Coordination of Humanitarian Affairs, WHO and World Vision.

The exercise identified 30 priorities for up-to-date systematic reviews of the effects of interventions, actions and strategies on health outcomes, which would be particularly relevant to those involved in Health EDRM at an international level. It built on a needs assessment that had identified a couple of hundred relevant research questions, which were grouped under 43 themes. Ten themes were prioritized through an online survey and the questions attached to these themes were discussed at a face-to-face meeting in London, United Kingdom in May 2013, leading to the generation of the list of 30 highest priority questions *(13)*.

There is a reasonable body of literature on the setting of priorities in healthcare research *(14)* and some attention has been paid to this issue in the context of Health EDRM. For example, the Radiological/Nuclear Threat Countermeasures Working Group identified and prioritized 18 areas for further attention in relation to radiological or nuclear threat countermeasures *(15)*. A formal process has also been developed for conducting a rapid review to identify research priorities, especially in regard to infectious disease outbreaks *(16)*. This resonates with the ethics of doing research (Chapters 3.4 and 6.4). Murray and Kessel highlighted the need for agreement on the prioritization process because

- Undertaking health and social research to help facilitate disaster risk reduction and disaster risk management is vitally important to increase preparedness to respond to disasters, to enable the most effective action to be taken once disasters have occurred and to understand better the consequences of disasters *(17)*.

UNICEF also stressed the need for formal methods of research prioritization in 2011:

- The efficiency of knowledge generation and dissemination at both the global and country levels is diminished by a lack of coordinated, systematic planning and rigorous evaluations. Insufficient coordination among HQ [UNICEF headquarters], ROs [regional offices] and COs [country offices] in establishing research priorities and planning evaluations detracts from development of a focused research agenda in ECD [early childhood development] and results in missed opportunities to leverage resources for more rigorous, longer-term country-specific and multi-country evaluations. Current processes at the country and global levels do not facilitate sequencing of evaluations into formative and summative stages. *(18)*

The framework presented in Table 3.5.1 can help when deciding on the relevance and relative priority of a new piece of research. This was suggested in a report on the impact evaluations that are already available or are needed for humanitarian assistance, prepared by Evidence Aid and the International Initiative for Impact Evaluation (3ie).

**Table 3.5.1. Framework for planning an impact evaluation *(19)***

| Item | Things to consider |
|---|---|
| **Feasibility of undertaking impact evaluations** | Consider methodological difficulties (for example in finding comparison groups), operational difficulties (for example in defining and delivering the policies, interventions, actions or strategies to be evaluated) or institutional difficulties (for example unwillingness to evaluate). |
| **What to evaluate?** | Consider whether the impact evaluation should be of a topic that will be particularly easy or difficult to evaluate. For example, it might be relatively easy to do a randomized trial of a specific medical procedure for treating cholera but examining a complex intervention to improve the protection of women and children in a displaced person camp might require the assessment of a range of difficult-to-measure outcomes (such as gender-based violence, dignity and livelihoods). |

| Item | Things to consider |
|---|---|
| **Use of existing evidence when prioritizing individual impact evaluations** | Consider whether to focus on areas with little or no existing research or areas with a relatively large amount of research that is not sufficiently reliable or robust. |
| **Creating review standards** | Review the existing evidence to confirm that there is sufficient uncertainty to justify a new study and, when it is complete, place its findings in the context of other relevant studies, to provide users with an up-to-date summary of the evidence base. |
| **Choosing the interventions to evaluate – innovation** | Consider whether to focus on innovative interventions or those that are already in wide use. |
| **Choosing the interventions to evaluate – relationship with the development sector** | Consider whether to focus on interventions where there is considerable overlap with the development sector. |
| **Choosing the interventions to evaluate – uncertainty, controversy and debate** | Consider whether to focus on policies or interventions with considerable uncertainty, controversy or debate about their relative effects. |
| **Choosing the populations to study** | Consider whether to focus on particular subgroups of people (such as vulnerable or disadvantaged), or the population as a whole. |
| **Settings for the impact evaluations** | Consider whether to focus on sudden-onset disasters (possibly with the need to put some impact evaluations ‘on the shelf’ for future events) or for ongoing protracted emergencies. |
| **Phases for the impact evaluations** | Consider whether to focus on impact evaluations in resilience, risk reduction, immediate short-term response, or prolonged response or engagement. |
| **Choosing the outcomes to measure** | Consider whether an existing core outcome set should be used, or a new one developed (see below). In the absence of a core outcome set, identify and measure those outcomes that will be most helpful to future decision makers. |
| **Methodology research** | Consider whether research into the methods to be used in the study could be embedded in the study, for example in a SWAT (Study Within A Trial) *(20)*. |
| **Impact evaluation of the impact evaluations** | Consider whether the study should include an evaluation (either by the research team working on the study or by someone independent) of the impact of the study on future policy, practice and outcomes. |
| **Dissemination and implementation of findings** | Consider having an implementation or knowledge translation plan, which should include how best to reach key decision makers and how the findings might be made available to those who took part in the study. |

## 3.5.7 Choosing the right outcomes to measure

Regardless of the topic chosen, the outcomes measured need to be those that will answer the research question reliably and be most useful to decision makers. Some of the causes of waste in healthcare research generally are the inconsistent measurement of outcomes across studies of the same topic, and selective reporting of the outcomes that have been measured *(9, 21)*. One way to reduce this waste is through the development of agreed, standardized sets of outcomes for research, known as core outcome sets. A core outcome set would help when comparing, contrasting and combining the findings of Health EDRM research. Although a core outcome set is not yet available for humanitarian action, a template has been prepared showing the data that should be reported for acute disaster medical response. This includes 15 data elements with indicators that can be used for research and quality improvement (Case Study 3.5.4). Furthermore, the international COMET Initiative *(22)* provides support for the development and uptake of core outcome sets and has identified more than 300 examples across health and social care *(23-25)*.

### Case Study 3.5.4
### Template for uniform data reporting of acute medical response in disasters

In order to tackle the lack of standards for collecting and reporting data in research studies on disaster medical management, the Academy for Emergency Management and Disaster Medicine brought together a group of 16 experts in the fields of research, education, ethics and operational aspects of disaster medical management from eight countries in a consensus process. Their aim was to produce a template for uniform data reporting of acute disaster medical response. The intention was to support more accurate completion of reports on disaster medical response, which would in turn contribute scientific evidence and knowledge that could be used to optimize medical response system interventions and improve the outcomes of disaster victims. The template was finalized at a meeting at the Utstein Abbey, on the island of Mosterøy, off the coast of Stavanger, Norway in November 2010. It followed the Utstein model, in which meetings are characterized by strong international collaboration and sponsorship of scientific organizations, using a process of gathering in an isolated intellectual environment experts who engage in well-facilitated discussions. The template contains 15 data elements with indicators, that can be used for both research and quality improvement, and it is available in the journal article *(26)*.

## 3.5.8 Being research ready

Chapter 3.6 describes how a scoping review might be the next step in moving forward with a piece of research. Sometimes, a pilot or feasibility study might be needed to develop the methods for a definitive research study and to ensure that it can be completed successfully. These might be particularly important steps when planning a study for implementation in a sudden-onset disaster, when it may be necessary to have plans for a prospective study (such as a randomized trial) pre-prepared and ready to be activated. Without this "on the shelf" study, it might not be possible to do the necessary research, especially if it would take days or weeks to design and activate the study and the need and opportunity for the research would therefore be missed. To overcome this challenge, it might be worth having the study pre-designed and ready to initiate at the appropriate time in the disaster. This is the case with a series of studies funded by the United Kingdom's National Institute for Health Research, which will be activated in the event of an influenza pandemic *(27)* and include a randomized trial of steroids for the critically ill *(28)*.

### 3.5.9 Conclusions

There are many areas of uncertainty in Health EDRM which would benefit from research. However, before embarking on any new study it is important that it is carefully planned and designed. The first step in doing this should be the development of a precise research question to help ensure that the design of the resulting study is appropriate and will produce a relevant, reliable and robust answer.

### 3.5.10 Key messages

- **Defining a clear research question, including any comparisons that will be made, is vital when planning a research study to fill an evidence gap for Heath EDRM.**
- **Outcomes to be measured and reported should be chosen carefully, in order to allow the study to answer the research question and provide evidence that will influence decision makers.**
- **A review of the existing evidence will help to ensure that the new study is a priority and that the answer to its research question is not available from existing research.**
- **If the study will need to be implemented rapidly (such as in a sudden-onset disaster), a pilot or feasibility study may be necessary and it will be important to have the design "on the shelf" and ready to activate.**

### 3.5.11 Further reading

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# 3.6

# Assessing the problems and developing a scoping review

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## 3.6.1 Learning objectives

To understand the role of scoping reviews when planning research in health emergency and disaster risk management (Health EDRM), including:

1. Scoping reviews as a research methodology.
2. Application of the methodology, including the steps involved and reporting of findings.
3. Tools that facilitate the scoping review process.

## 3.6.2 Introduction

A scoping review is a research method which synthesizes the available evidence in a subject area. Although relatively new, it is an increasingly popular approach in health sciences and research *(1)* and can make an important contribution to Health EDRM. It is used to examine the extent, range and nature of research activity; to determine the value of undertaking a full systematic review (see Chapter 2.6); to summarize and disseminate research findings; and to identify research gaps in the existing literature (see Chapter 3.7) *(2)*.

While scoping reviews are similar to systematic reviews in their utility, a key difference emerges when it comes to the research question or objective. The nature of the scoping review as a ‘reconnaissance tool’ means that it typically has a broader scope, and so the research question tends to be less focused than in a systematic review. Consequently, the inclusion criteria for scoping reviews are wider and may be defined both a priori and post hoc. Another element that differentiates scoping reviews from systematic reviews is the lack of a formal quality assessment process. This is again linked to the nature of the scoping review for which the main goal is to map the available evidence rather than to produce a response to the research question by synthesizing evidence from critically appraised documents. However, in spite of these differences, like systematic reviews, scoping reviews must adhere to the principles of transparency, validity, and reproducibility.

This chapter outlines and describes the scoping review methodology and uses two case studies as examples to illustrate the process.

## 3.6.3 Methods

Arksey and O'Malley *(1)* first proposed a methodological framework for conducting scoping reviews in 2005. However, since then it has undergone several revisions and modifications. In 2012, Levac and colleagues reviewed and made recommendations on how to improve scoping reviews *(2)*. Subsequently, Peters and colleagues proposed guidance for scoping reviews based on the methodology developed by members of the Joanna Briggs Institute and Collaborating Centers *(3)*. In 2018, Tricco et al, developed an extension to Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) for the reporting of scoping reviews with the aim of improving the quality of the methodology and its reporting *(4)*.

A scoping review can be viewed as a five-step process, which includes:

i) identifying the research question

ii) identifying relevant studies

iii) selecting relevant studies

iv) charting the data

v) collating, summarizing and reporting the results.

Arksey and O'Malley also recommend the additional but optional step of carrying out a consultation exercise to inform and validate the findings of the literature review *(1)*.

## 3.6.4 Identifying the Research Question

The first step of the scoping review process is to create a review team, which should include people with expertise in scoping reviews and where possible, the subject matter, such as Health EDRM. The review team should also includelibrarians *(5)* (Chapter 6.2). Co-production and collaboration among people with such a diverse range of skills and experience will ensure that the research proceeds in a logical, scientific manner that is aligned with and builds on the existing knowledge in the subject area.

When the review team has been created, the next step is to identify the objective of the review and, based on this, define the research question (see Chapter 3.5). The scope should be as wide as possible, to allow the review to capture as much of the available evidence as possible, but this should be balanced against practicalities such as feasibility, time and resource constraints *(2)*.

Next, a scoping review protocol should be developed and published. The protocol should contain the rationale for the review, its objectives, detailed information on the methodology, including the inclusion and exclusion criteria, and an account of how the findings will be disseminated *(6)*. This will guide the research process, ensure transparency and help to reduce duplication of efforts by researchers who undertake similar studies in the future.

### 3.6.5 Identifying Relevant Studies

The next step is to identify the relevant literature, which begins with defining the search strategy and identifying the key concepts in the research question (see Chapter 6.2). This is an activity which should, where possible, be done together with a librarian. Defining the search strategy involves identifying the keywords, subject terms, themes and phrases related to and based on the key concepts as well as their synonyms. When this has been done, other limits such as the type and language of the publication and the period that the review will cover should be defined. Finally, the databases to be searched should be identified. The identified keywords, subject terms, themes and phrases should be combined and applied to each of the selected databases, bearing in mind that such combinations (and the search strategy as a whole) may need to be adapted for the different databases. A good approach is to carry out preliminary searches to test the process, and refine it if necessary, before undertaking the definitive search. The search should include searches of protocol registries and be followed by hand-searching of key journals and checking the reference lists of relevant articles, in order to minimize the possibility of missing relevant documents.

The process described above generally identifies peer-reviewed literature but may omit important documents like grey literature – that is, information produced and found outside of traditional publishing and distribution channels, such as presentations, reports, theses, conference proceedings, policy statements and working papers produced by government, inter- and nongovernmental organizations, professional networks or other organizations. Therefore, the peer-reviewed literature search should, where possible, be reinforced by a grey literature search, in order to ensure a more comprehensive capturing of the evidence and reduce the risk of reporting bias. Grey literature can be found through searches using online search engines and targeted searches on the websites of relevant and related organizations.

The search process and results of the searches conducted should be documented as meticulously as possible, in order to maximize recall, and to ensure that it can be reported and reproduced accurately. It is important to keep a record of the databases searched, the dates each search was done, and the results that were produced. Data management tools such as spreadsheets and bibliographic software packages such as Reference Manager or Endnote, can be useful for this. The search strategy should be included in the review report.

### 3.6.6 Study Selection

The third step in the scoping review process is the selection of relevant articles and studies, which is performed by a team of people who screen the articles retrieved in the search. This begins with a definition of the inclusion and exclusion criteria based on the scoping review's research question and objectives and involves describing the characteristics that eligible studies must possess. These criteria may be defined before or after the search, but a good approach is to draw up a preliminary list of criteria which can be reviewed and refined after the initial search and emerging themes become more apparent. The criteria will guide the people screening the articles for inclusion and ensure consistency in decision-making around the selection of articles to be included in the review.

Study selection should be carried out by at least two screeners, each of whom document and report their decision making. This should begin with a rapid screening of the titles and abstracts, to eliminate irrelevant studies or those which do not respond to the eligibility criteria. This can be done manually or might be helped through the use of software tools such as Abstrackr, Covidence, SRA-Helper for EndNote, Rayyan and RobotAnalyst, DistillerSR: details of these tools and others can be found online *(7)*. Using software can facilitate, speed up and improve the efficiency of the abstract screening process *(8)*. In most cases, the search results can be uploaded to the screening platforms either directly from databases, or from bibliographic management tools and spreadsheets. They also allow labels to be attached to processed references, which are indicated and displayed to each member of the screening team. This enables collaborative and concurrent work among multiple screeners, with each being able to make independent decisions about which articles should be included or excluded.

Following the initial selection, the full texts for the articles should be obtained and checked against the review's inclusion and exclusion criteria. This requires a reading of each article and a decision about whether it should be included in the review. The final selection should be done independently by at least two people to minimize bias and error. In case of disagreement, decisions should be evaluated and discussed as a team until consensus is reached *(2)*. This may involve seeking the input of a more senior team member. Any deviations from the scoping review protocol should be documented and reported.

### 3.6.7 Charting the Data

This is the process of recording the characteristics of the reviewed documents and keeping a record of the extracted information, in a systematic way. Such records should include general information such as the article's authors, title, type and date of publication and country of origin; study characteristics including the aim and objectives of the study; design and methodology; population characteristics; intervention; outcomes or results; subject areas or themes; and other relevant notes. The extracted data can be stored in simple spreadsheets such as Excel, but dedicated software is also available, including those mentioned above to help with screening as well as Sysrev *(9)*, SRDR *(10)*, the Joanna Briggs Institute's System for the Unified Management, Assessment and Review of Information (JBI SUMARI) *(11),* TableBuilder *(12)*. To minimize error, everyone working on data extraction and charting should use a standardized extraction sheet which has been designed collaboratively.

### 3.6.8 Collating, Summarizing and Reporting the Results

In this stage, the review process should be summarized and presented in a comprehensible manner. The information can be organized and displayed using tables and flow charts such as the PRISMA diagram *(9)*, which illustrate the search and selection processes.

The results should be synthesized, analysed and used to generate responses to the research questions for the review. The findings should be collated and presented in a format that facilitates easy understanding for readers and the report should also contain information on the data analysis and synthesis methods used *(13)*.

Guidance on good reporting of scoping reviews are available in a special extension to the PRISMA guideline, which includes a checklist, as well as examples and explanations of best practices for reporting the findings of scoping reviews *(4)*.

Case Studies 3.6.1 and 3.6.2 provide examples of scoping reviews of the evidence base for disaster management in low- and middle-income countries (LMIC) and primary research in public health emergency preparedness (PHEP). The first study *(14)* reviewed existing evidence on emergency planning in health for LMIC settings with a particular focus on studying how it differs from high-income countries. The focus was mainly on searching the literature. In the second review *(15)*, the aim was to get a comprehensive overview of PHEP stakeholders were therefore consulted to ensure that no crucial areas or documents were overlooked. The consultation exercise also served to validate the findings from the literature based on the stakeholders' knowledge and experience. This highlights how scoping reviews are not a 'one size fits all' activity, but rather an exercise that should be closely aligned with and adapted to the research question and objectives.

### Case Study 3.6.1
### Disaster management in LMICs: scoping review of the evidence base

This study reviewed the evidence on emergency planning in health for LMIC settings with a particular focus on studying how it differs from high-income countries.

A search strategy was developed by compiling the themes and topics relevant to the topic and using them to generate search terms that were then applied in a pilot search. The search strategy was then adapted and applied to six electronic databases: Embase, The Medical Literature Analysis and Retrieval System Online (MEDLINE), PsycINFO, Biosis, Science Citation Index, Cumulative Index of Nursing and Allied Health Literature (CINAHL) and the Cochrane Library. The search was limited to articles published between 1990 and 2011.

The citations generated were downloaded into a reference manager database and duplicates were excluded, resulting in 2652 articles to be screened. A title and abstract review and thematic coding was done by the members of the reviewing team; disagreements regarding the relevance or categorization of articles were resolved through discussion and collective reviewing until a consensus was reached. 1545 articles were eventually selected for review. The characteristics of the reviewed documents, as well as extracted information from the studies themselves were recorded. This included a categorization of the results according to country of origin of articles, type of report and type of disaster, and thematically according to income classification and phase of the disaster management cycle *(14).*

### Case Study 3.6.2
### The evidence base of primary research in PHEP: a scoping review and stakeholder consultation

This scoping review explored existing research on PHEP and identified knowledge gaps.In consultation with a library specialist, the reviewers developed a search strategy with search terms relevant for public health, emergencies or disasters, emergency preparedness or emergency management and evidence or evaluation. This search strategy was applied to MEDLINE, Embase, BIOSIS, PsycInfo and Ebsco (CINAHL, Academic Search Premier, Health Business Elite, Environment Complete and SocINDEX). The search was restricted to the years 1998-2013 but designed to include key emergency events. In a second phase, the reference lists of included articles were checked for further articles. Finally, a Google search was done and other relevant sources were consulted to find grey literature.

The database search produced 3631 citations, which after duplicate and title screening, resulted in 322 articles for the selection stage of the review. Together with the 74 results generated from the other searches, two researchers independently reviewed all the articles for possible inclusion based on the following inclusion criteria:

- Does the article specifically include the actions of Public Health (local, province/state or national level)?
- Does the article include public health actions in aspects of emergency management such as prevention/mitigation, preparedness, response, and/or recovery?
- Does the article include an evaluation of public health actions during an emergency event (whether based on qualitative or quantitative data) OR propose emergency management-related standards or best practices that have been derived from a process with clear methods?

The characteristics of the studies were charted, and the information extracted was coded and analysed using the thematic analysis approach.

The next stage was a consultation with key informants which began with a survey to elicit their feedback on the key themes identified during the document review, and the identification of any themes or relevant documents that had been overlooked in the review. The consultation stage was concluded with a face-to-face working group meeting to validate the findings of the previous stages of the review *(15).*

### 3.6.9 Consultation Exercise

Although there is some debate around the necessity of having a consultation stage such as that noted in Case Study 3.6.2, it is recommended that this stage of the process be included where possible. It should include subject experts and other key informants. The information generated from such an exercise allows for triangulation with the findings from the literature and so helps to validate the findings of the scoping review.

### 3.6.10 Conclusions

This chapter has described the general principles of the scoping review methodology. More information is available in the suggestions for further reading. A more in-depth explanation of how to apply the methodology in health policy and systems research in both routine and emergency contexts has also been prepared by Tricco and colleagues *(16)*.

### 3.6.11 Key messages

- **Scoping reviews map and synthesize the available evidence in a given subject area.**
- **They can be used to gauge the extent, range and nature of research activity, determine the value of undertaking a more formal systematic review, identify research gaps and develop a research agenda.**
- **While scoping reviews differ from systematic reviews, they are not substandard systematic reviews, rather, they are a research methodology in their own right. They should therefore adhere to good research principles of transparency, validity and reproducibility.**

### 3.6.12 Further reading

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10. Systematic Review Data Repository (SRDR). https://srdr.ahrq.gov/
11. The System for the Unified Management, Assessment and Review of Information (SUMARI). The Joanna Briggs Institute. https://www.jbisumari.org/
12. TableBuilder [data tool]. Australian Bureau of Statistics. https://www.abs.gov.au/websitedbs/censushome.nsf/home/tablebuilder
13. Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group. Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Medicine. 2009: 6(7): e1000097.
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15. Khan Y, Fazli G, Henry B, de Villa E, Tsamis C, Grant M, et al. The evidence base of primary research in public health emergency preparedness: a scoping review and stakeholder consultation. BMC Public Health. 2015: 15(1): 432.
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# 3.7

# Research resources to support policy and new research

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## 3.7.1 Learning objectives

To understand:

1. Some of the key information resources that can be used to find existing research into the effects of interventions relevant to health emergency and disaster risk management (Health EDRM);
2. How to access these resources; and
3. How the evidence from this research might be used in decision making.

## 3.7.2 Introduction

Evidence derived from evaluation and research into the effects of interventions relevant to Health EDRM can help policy makers and practitioners to understand what works, where, why and for whom *(1)*. Not only can evidence from research be used to help design interventions that effectively mitigate health and disaster risks, it can also help policy makers and practitioners avoid interventions which may cause harm, and avoid repeating the mistakes of the past.

This chapter explores some of the sources of such high-quality research evidence and how these can be accessed by policy makers and those designing new research studies; by accessing this existing research evidence, they will be better able to set well-informed policies and to design future research that will fill important gaps. This is explored in greater detail elsewhere in this book. For example, see Chapter 3.6 for the key steps in conducting a scoping review before embarking on a new study and Chapter 6.2 for information on how to search for literature and research evidence that might be used to support a proposal for a new study.

## 3.7.3 Challenges faced by policy makers looking for research evidence

Researchers and policy makers face several challenges when looking for research evidence on the effects of interventions that might be relevant to Health EDRM. The first is common to many fields and is the frequently contested nature of ‘evidence’ itself *(2)*. Scientific principles of proof, validity and reliability, or research frameworks in which credible steps have been taken to minimize bias, may find themselves crowded out by expert opinion, established ways of working (“we’ve always done it this way”) or ideological policy making (“we believe this is the right way to do things”). To some extent, resistance from policy makers and practitioners in health emergency and disaster management who feel that evidence is no substitute for experience, expertise and localized knowledge reflects a reasonable concern – research evidence showing what works is seldom definitive, and because it may have been generated under ideal or highly controlled circumstances, it often lacks ‘real world’ implications. Also, research evidence does not tell decision makers what to do or how to act. In the context of interventions, it merely indicates the likelihood of certain outcomes being achieved based on a rigorous comparative analysis with doing something else (Chapter 4.1). In other contexts, it might, for example, tell them about risk factors (Chapter 3.2) or how common a particular problem is likely to be after a disaster (Chapters 2.1, 2.2 and 2.4). Such research evidence requires interpretation and judgement by decision makers based on their experience, substantive expertise, and *in situ* knowledge.

Secondly, the complexity of disaster settings and the difficulties of conducting research in such environments may mean that high quality, relevant evidence is not available. For instance, there are relatively few controlled impact evaluations using experimental or quasi-experimental designs compared to other sectors (3) and, therefore, fewer systematic reviews of the effects of interventions. Blanchet and colleagues (1) have noted that it might be impossible to use a randomized trial to compare the relative effects of different ways to coordinate the response to a major emergency, or the impact of a national policy intended to improve the social inclusion of refugees. In such cases, researchers might use a quasi-experimental design to investigate the link between the interventions and the outcomes” (See Chapters 4.14 and 4.15). Puri and colleagues *(4)* listed some factors that limit the use of controlled evaluations in the broader humanitarian sector. These include:

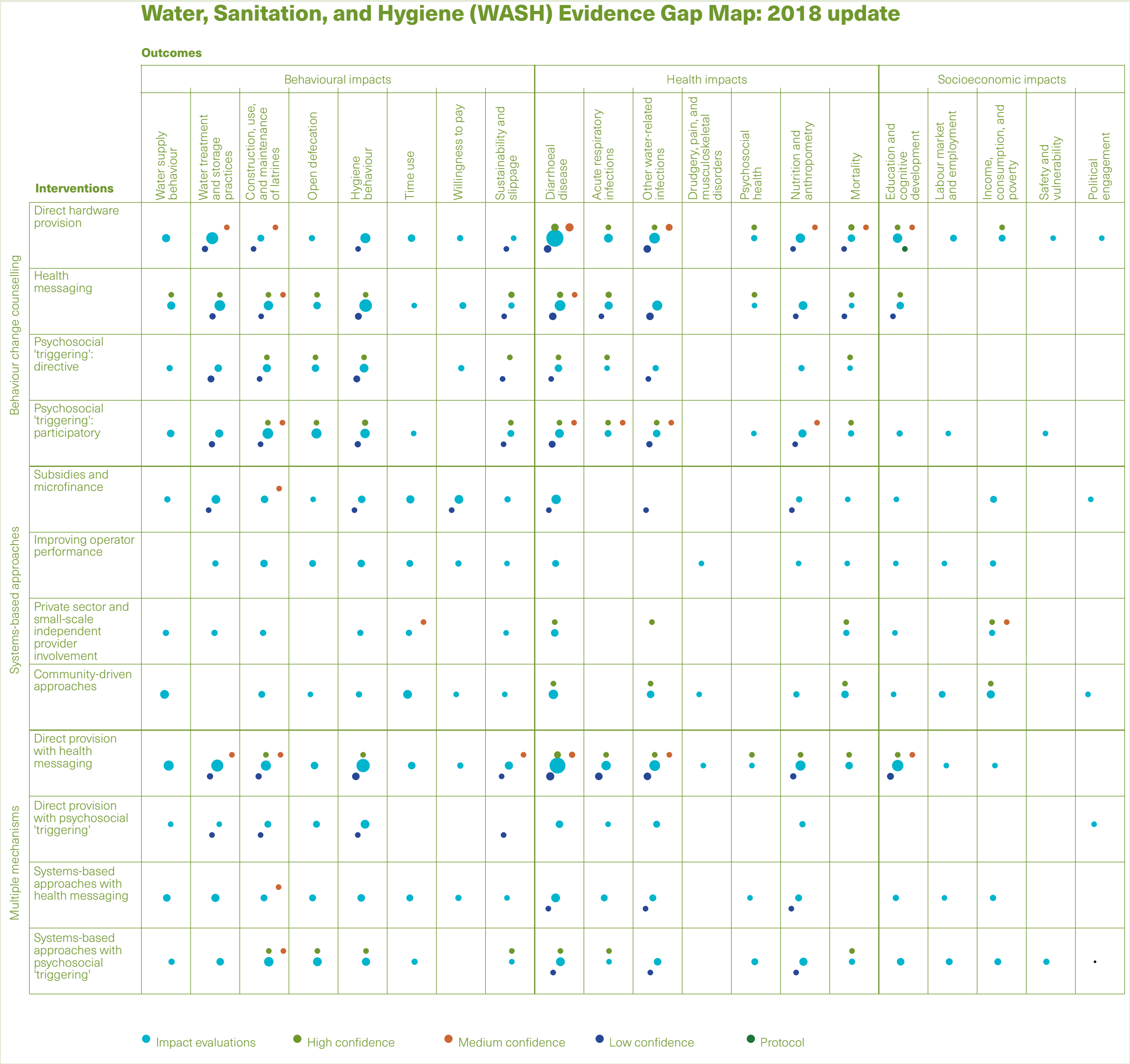
- the urgency of humanitarian action, which makes advance preparation for evaluation very difficult;
- the absence of baseline data and the inability to plan for and construct counterfactuals;
- the multiplicity of agencies providing support in any one area, which makes it difficult to decouple actions and outcomes;
- the fact that conflict and disasters do not usually have clean boundaries means that it is also difficult to find or establish comparable groups that can serve as counterfactuals in a scientifically robust and ethically sound way;
- a lack of impact evaluation experts in the humanitarian sector and a lack of humanitarian experts in the impact evaluation sector.

Notwithstanding these challenges, there is a growing body of evidence from experimental and quasi-experimental evaluations, and systematic reviews, as to what works, and what does not work, in disaster settings (see Case Study 3.7.1).

## Case Study 3.7.1
## Mapping and synthesizing the evidence base

3ie (The International Initiative for Impact Evaluation) was established in 2008 to support the generation and effective use of high-quality evidence to inform decision-making and improve the lives of people living in poverty in LMICs. 3ie now offers several searchable databases online. Two of these, the 3ie Database of Systematic Reviews and the Database of Impact Evaluations catalogue evidence of the effectiveness of interventions in the humanitarian sector. These databases also include systematic reviews and impact evaluations on the broader landscape of international development, many of which have relevance to interventions in emergency situations. Furthermore, 3ie's evidence gap maps provide a visual display of completed and ongoing systematic reviews and impact evaluations in a sector or subsector, structured around a framework of interventions and outcomes (for an example, see Figure 3.7.1). They provide both researchers and policy makers with a valuable 'at a glance' view of the quality of the existing evidence base and the confidence with which a link between particular interventions and outcomes can be established.

**Figure 3.7.1 Example of a 3ie gap map, on water, sanitation and health***



*reproduced by kind permission of 3ie

However, where high quality research exists, it may be difficult to find, written in complex language or in a language other than that spoken by those responding to a disaster. The vast number of opportunities for researchers to publish or present their studies means that relevant studies may be scattered across tens of thousands of reports, thousands of websites and journals, or hidden within closed databases or behind paywalls. Even where research can be found on relatively established databases such as PubMed, Global Index Medicus (which includes the Latin American And Caribbean Health Sciences Literature database, LILACS), ERIC and OpenGrey, sifting through such evidence can be daunting and may require the services of an information specialist (see Chapters 3.6 and 6.2). For policy makers and practitioners, this means it is often difficult to understand what evidence actually exists even though they wish to use it *(5)*. For researchers, it may be challenging to see what gaps are present in the evidence base and hence where to direct scarce research resources.

## 3.7.4 The evidence base for interventions in health emergency and disaster settings

Research synthesis is one solution to the problem of finding research studies. Research synthesis has been described as "the most important single offering by academics to the policy process" *(6)*. Research synthesis is increasingly used in disaster preparedness and response, and humanitarian action to develop evidence-based guidelines and design interventions *(7)*. For example, WHO seeks to support its guidelines with research evidence that has been brought together in systematic reviews *(8)* and several organizations (Table 3.7.1) seek to make available details of systematic reviews on a wide range of humanitarian- and disaster-related topics. These include Enhancing Learning and Research for Humanitarian Assistance (ELRHA), the Global Health Institute (GHI) at the American University in Beirut, Lebanon and Evidence Aid. Case Study 3.7.2 provides an example of how Evidence Aid organized systematic reviews relevant to malnutrition into one of its broader thematic collections *(9)*.

Some international disaster response agencies, such as the International Rescue Committee, are also making increasing use of systematic reviews and other forms of research synthesis to underpin intervention design (Case Study 3.7.3).

### Case Study 3.7.2
### Special collection of systematic reviews of interventions for the prevention and treatment of moderate and severe acute malnutrition relevant to humanitarian and disaster settings

The use of evidence to inform policy making can often be hampered by the sheer diversity, complexity and inaccessibility of evidence. Relevant research may be dispersed across many databases, may not be publicly available and requires assessment of its relevance to ensure generalizability to a given risk or context. Furthermore, there may be barriers to research uptake that are nothing to do with the accessibility, relevance or complexity of the evidence itself, but rather with the value attached to that evidence by policy makers.

By working with multistakeholder, multidisciplinary groups of specialists to curate and produce its research synthesis products, Evidence Aid seeks to address both the inherent challenge of conducting research synthesis relating to disaster settings and the potential challenges of research uptake. Working with groups that include policy makers and practitioners as well as researchers allows it to capture the broadest range of relevant and robust research evidence, and also to generate an enhanced sense of 'ownership' over the evidence base from those whose job it is to design interventions.

Between March 2017 and March 2018, Evidence Aid brought together a group of 21 stakeholders from a variety of backgrounds to review and curate a collection of systematic reviews of interventions for the prevention and treatment of moderate and severe acute malnutrition relevant to humanitarian and disaster settings *(9)*. The methodology loosely followed general guidance for overviews of systematic reviews, with a pre-defined question formulated using the population, intervention, comparison, outcome, study design (PICOS) format, and search strategies applied to multiple databases. Pairs of collaborators first screened the search yields to identify potentially eligible reviews; other pairs then screened the list of potentially eligible reviews for relevance and thus inclusion in the final collections. Search strategies were run in 12 databases yielding a total of 4646 records after de-duplication.

Through this collaboration, Evidence Aid successfully generated collections of systematic reviews to guide prevention and management of acute malnutrition in humanitarian emergencies. These collections, made available on its website, provide accessible, synthesized evidence that can be used to inform decision-making on strategies and policies in the humanitarian emergency and disaster risk reduction sectors and to guide future research by identifying gaps in robust evidence and areas that are under-researched *(10)*.

### Case Study 3.7.3
### Using research synthesis in practice

The International Rescue Committee (IRC) is a long-established international humanitarian agency that offers emergency aid and long-term assistance to refugees and those displaced by war, persecution, or natural disaster. IRC has been placing increasing emphasis on high-quality evidence in the development of programme guidance documents and tools for field staff. It does this by conducting evidence reviews across many high-quality sources around specific interventions or approaches, and using what it learns about impact, contexts, populations and conditions to inform whether and how to adapt those interventions.

IRC's agency-wide effort to ensure that evidence is readily available to staff is framed by its Outcomes and Evidence Framework *(11)*, a publicly available online platform in which it defines the outcomes and sub-outcomes that it wishes to focus on, the general theories of change or pathways through which it seeks to achieve those outcomes, and indicators for measuring them. For each outcome and sub-outcome, it has summarized the best available evidence on the effectiveness of relevant interventions, with a primary focus on evidence from systematic reviews. For topics where systematic reviews do not yet exist, IRC has identified and summarized individual studies. IRC's collection of systematic reviews is drawn from the databases of 3ie, the Campbell Collaboration Library, the Cochrane Library and the United Kingdom's Department for International Development (DFID) Research for Development website. IRC also has a collection of Evidence Maps on health, education, economic wellbeing, safety, and power, and cross-cutting maps that focus on cash transfer interventions, service delivery interventions, and interventions in humanitarian emergencies.

The increasing use of rapid evidence synthesis to inform health systems development in LMICs also opens up potential opportunities to support better evidence-based decision-making via research synthesis even in the midst of disasters *(12)*.

## 3.7.5 Repositories of research evidence and systematic reviews

In order to help bring research evidence together, repositories have been established of systematic reviews and high-quality evaluations that are relevant to Health EDRM. Using these resources can make it easier and more efficient for both researchers and policy makers to navigate the existing evidence base. Table 3.7.1 shows several of these repositories; an up-to-date list is available from Evidence Aid on its website *(13).*

### Table 3.7.1 Online repositories of systematic reviews, high-quality evaluations and research evidence relevant to Health EDRM

**3ie (International Initiative for Impact Evaluation)** (see also Case Study 3.7.1) www.3ieimpact.org

3ie was established in 2008 to support the generation and effective use of high-quality evidence to inform decision-making and improve the lives of people living in poverty in low- and middle-income countries. 3ie now offers several searchable databases online.

**Global Health Institute (GHI)** www.ghi.aub.edu.lb/about-us

The Global Health Institute was established within the American University in Beirut, Lebanon. Its library of resources reflects the outputs of its interdisciplinary programmes on conflict medicine, refugee health, and nutrition, obesity and related diseases. They have also formed strategic partnerships with local and international stakeholders in health, aspiring to strengthen South-North collaborations among organizations and academic institutions.

**Australian Disaster Resilience Knowledge Hub** https://knowledge.aidr.org.au/

This hub provides a national, open-source platform that supports and informs policy, planning, decision making and contemporary good practice in disaster resilience.

**Campbell Collaboration** www.campbellcollaboration.org

The Campbell Collaboration is an international research organization that publishes a library hosting a wealth of research and evaluation on the effectiveness of interventions in crime and justice, education, social welfare and international development, many of which have relevance for interventions in the humanitarian sector. The Campbell Collaboration also produces a Policy Brief Series and provides training for researchers in how to undertake systematic reviews.

**Centre for Evidence-Based Practice (CEBaP)** www.cebap.org

The Centre for Evidence-Based Pratice  is a non-profit global centre located in Belgium that uses scientific evidence to support humanitarian aid activities, including those of the Belgian Red Cross. The Centre uses systematic reviews to provide this evidence for a range of humanitarian activities, development programs and emergency relief.

**Cochrane Library** www.cochranelibrary.com

The Cochrane Library is an online publication offering a collection of high-quality, independent evidence to inform healthcare decision-making. Some of the reviews in the Cochrane Library have relevance for interventions in the humanitarian sector. The Cochrane Library is produced by an international organization called Cochrane (formerly 'The Cochrane Collaboration'), which also has a training arm that provides training in how to undertake systematic reviews, both online and at training events. Cochrane also publishes one of the leading handbooks for preparing and maintaining systematic reviews of the effects of interventions: training.cochrane.org/handbook.

**Department for International Development (DFID) Research for Development Library** https://www.gov.uk/dfid-research-outputs

The United Kingdom's Department for International Development is a major funder of research on international development, disaster relief and conflict. It has an online library of resources.

**Enhancing Learning and Research for Humanitarian Assistance (ELRHA)**
www.elrha.org/research-database

The Enhanced Learning and Research for Humanitarian Assistance is a global charity that seeks to find solutions to humanitarian problems through research and innovation. Its website hosts a free and easy to use resource library which holds every output from the work they fund as well as other publications, gap analyses, peer-reviewed journals, case studies and evaluations.

**Evidence for Policy and Practice Information and Co-ordinating Centre**
http://eppi.ioe.ac.uk/cms/

The Evidence for Policy and Practice Information and Co-ordinating Centre is based at University College London, United Kingdom. It covers a wide range of sectors, including the humanitarian sector, providing access to primary studies, systematic reviews and other types of evidence synthesis, including through its database of systematic reviews and database of primary research, which can be searched from its website.

**Evidence Aid** www.evidenceaid.org

Evidence Aid was founded by Cochrane staff to champion evidence-based decision-making in humanitarian action. Having initially worked by making the full text of several dozen Cochrane systematic reviews freely available online, it has now collated several hundred systematic reviews relevant to disaster settings, all of which are free to view on its website. Its resources also include Special Collections, which are bundles of reviews relevant to hazards (such as windstorms or earthquakes), specific disease risks (such as the Ebola and Zika viruses) or particular types of interventions (such as those relevant to prevention and treatment of malnutrition (Case Study 3.7.2).

**Harvard Humanitarian Initiative**
http://hhi.harvard.edu/resources#publications

The Harvard Humanitarian Initiative is a dedicated humanitarian research initiative at Harvard University, USA. It brings an interdisciplinary approach to promoting understanding of humanitarian crises and global health problems, and to developing evidence-based approaches to humanitarian assistance. Its Humanitarian Academy is dedicated to educating and training current and future generations of humanitarian leaders.

**Health in Humanitarian Crises Centre**
https://www.lshtm.ac.uk/research/centres/health-humanitarian-crises-centre

The Health in Humanitarian Crises Centre is based at the London School of Hygiene and Tropical Medicine, United Kingdom. It generates primary research and systematic reviews on public health in humanitarian crises, working closely with international humanitarian agencies and research centres in affected countries to address critical health challenges. A four-year research and capacity-building programme, RECAP was launched in 2018, focusing on decision-making and accountability in response to humanitarian crises and epidemics.

**Humanitarian and Conflict Research Institute (HCRI)**
https://www.hcri.manchester.ac.uk/

The Humanitarian and Conflict Research Institute is based in Manchester University, United Kingdom. It is a global centre for the study of humanitarianism and conflict response, global health, international disaster management and peacebuilding. Its library of research includes many studies on the effectiveness of interventions in areas such as health, wellbeing, social justice and peace-building.

**International Rescue Committee (IRC)** (see also Case Study 3.7.3)
www.rescue.org

IRC is a long-established international humanitarian agency that offers emergency aid and long-term assistance to refugees and those displaced by war, persecution, or natural disaster. It places an emphasis on high-quality evidence in the development of programme guidance documents and tools for field staff by conducting evidence reviews across many high-quality sources around specific interventions or approaches.

**Johns Hopkins Center for Humanitarian Health**
http://hopkinshumanitarianhealth.org/research/publications

The Johns Hopkins Center for Humanitarian Health is hosted at and administered by the Bloomberg School of Public Health, USA. The centre draws upon a variety of disciplines, including epidemiology, demography, emergency and disaster medicine, health systems management, nutrition/food security, environmental engineering, mental health, political science and human rights. Its library of resources includes many studies on evidence-based strategies for prevention, preparedness, response, recovery and reintegration.

**Oxfam** https://policy-practice.oxfam.org.uk/

Oxfam's Policy and Practice website offers free access to thousands of publications including training manuals, evaluations, research reports and policy briefs, as well as programme overviews, staff profiles and their practitioner blogs. It also includes a collection of systematic reviews and other types of evidence synthesis relevant to humanitarian emergencies.

**Tufts University / Feinstein International Center's Humanitarian Evidence Program**
https://fic.tufts.edu/research-item/the-humanitarian-evidence-program/

Tufts University / Feinstein International Center's Humanitarian Evidence Program produced a series of reviews to distil humanitarian evidence and communicate it to key stakeholders in order to enable better decision-making and improve humanitarian policy and practice. The initiative was a Department for International Development-funded partnership between Oxfam and the Feinstein International Center.

**UNICEF – Office of Research-Innocenti** www.unicef-irc.org/publications/series/methodological-briefs

UNICEF – Office of Research-Innocenti collaborated with Royal Melbourn Institute of Technology University, Better Evaluation and 3ie to produce methodological briefs and videos on counterfactual evaluation designs. The series covers the building blocks of impact evaluation, strategies for causal attribution, and different data collection and analysis methods.

**WHO Health Emergencies Programme (HEP) / Humanitarian Health Action (HHA)** www.who.int/hac/techguidance/en

WHO Health Emergencies Programme/Humanitarian Health Action works with countries and partners to prepare for, prevent, respond to and recover from all hazards that create health emergencies, including disasters, disease outbreaks and conflicts. The Humanitarian Health Action website includes technical guidance based on available evidence on a wide range of health emergency topics.

### 3.7.6 Conclusions

Policy makers and practitioners in Health EDRM can and should make systematic use of high-quality evidence to inform operational and strategic decision making. Likewise, researchers should consider the evidence from existing research before embarking on a new study (Chapter 2.6). Those who fund and commission research and evaluation in disaster-affected settings should publish what they fund on open access platforms where possible and these studies should be brought together in systematic reviews. Not doing so risks rendering the investments in research ineffective and contributes to publication bias. While the increasing number of studies and variability in study design may make it difficult for policy makers to understand and appraise the growing evidence base, systematic reviews and other forms of research synthesis offer effective pathways to bring evidence to bear on policy and practice. Furthermore, resources that collate these reviews, such as those described in this chapter, make it much easier for those who need and those who should use this synthesized research to find it.

### 3.7.7 Key messages

- **Evidence derived from evaluation and research of the effects of interventions relevant to Health EDRM can help policy makers and practitioners to understand what works, where, why and for whom, and to avoid interventions which may cause harm.**
- **There are a growing number of existing quality studies relevant to Health EDRM, but these can be difficult to access or to analyse in their 'raw' state.**
- **Systematic reviews and other forms of evidence synthesis may offer a pathway to turn this high-quality evidence into sound policy and effective interventions.**
- **Many such reviews are available in free-to-access repositories such as those listed in this chapter.**

### 3.7.8 Further reading

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11. The Outcomes and Evidence Framework. International Rescue Committee. oef.rescue.org
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# Study design

## 4.0

# 4.1

# Basic principles in designing studies to assess the effects of interventions

## Authors

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## 4.1.1 Learning objectives

To understand key factors to consider when developing a study to assess the effects of an intervention, action or strategy for health emergency and disaster risk management (Health EDRM), including:

1. The importance of reliable and robust estimates of the effects of interventions.
2. Minimizing the risk of bias.
3. The role of randomized trials.
4. Aspects of conducting prospective, comparative studies.

## 4.1.2 Introduction

This chapter will show how research can provide reliable and robust evidence about the likely effects of different interventions in order to help people choose between alternatives when there is more than one intervention suitable for an individual, or a variety of actions or strategies that are appropriate for a population. To be reliable, this evidence needs to come from studies in which the interventions were compared in ways that minimize the effects of biases *(1)*, such as biases that might arise from using information about a participant's likely outcomes to select who will or will not receive one of the interventions being compared. To be robust, the studies also need to be large enough to minimize the effects of chance.

This chapter outlines how such studies might be carried out in the Health EDRM context and highlights important features for the design, conduct and interpretation of such studies. The various types of research design that might be used to study different areas of importance to Health EDRM are discussed in Chapter 3.5. In this chapter, particular emphasis is placed on a type of comparative effectiveness study called a randomized trial, because this design seeks to minimize bias and generate reliable and robust estimates of the relative effects of interventions. It does this by creating comparison groups that differ only in regard to the interventions being compared. In randomized trials, some of the individuals who join the study are randomly allocated to receive the intervention being tested, which might be a new way of protecting people from contaminated water, a treatment for fractures or a treatment to minimize anxiety, for example; this is often called the experimental group. The other participants in the trial would be allocated to an alternative intervention or a control group. Cluster randomized trials are a modified version of this design, when randomization is done at the level of clusters (such as families, villages or hospital wards), rather than at the individual level. These are discussed in Chapter 4.3.

Randomized trials seek to answer research questions about cause and effect in a controlled manner. Their aim is to produce an estimate of the impact or effect of the intervention by comparing the outcomes in the experimental group to those in the control group. The purpose of this is to generate evidence, which can then be used to make assumptions about how the intervention might affect people who are similar to those in the trial.

However, although we focus here on randomized trials, many of their key features discussed below are also applicable to other prospective studies in which individuals are recruited and followed up.

### 4.1.3 Why do we use randomized trials?

Randomized trials are prospective studies in which eligible participants are randomly allocated to one of the two or more groups that are to be compared, with each group receiving a different intervention. This allows a comparison to be made of how each intervention affects the outcomes that are measured — such as the speed of a person's recovery, their quality of life, or how well they understand information about a disaster-related threat to their health or livelihood. However, for some research questions – on topics such as estimating the proportion of people who have different levels of mental or physical trauma after an earthquake, for example – other study designs would be used; these are discussed elsewhere in this book, such as in Chapter 3.2 for assessing risk factors.

### 4.1.4 Planning the trial: eligibility criteria

Chapter 3.5 discussed the importance of having a clear research question for a study, including the need to match the research question to the comparison to be made in a randomized trial, using the example of fish oil for PTSD. Case Study 4.1.1 describes a randomized trial undertaken with rescue workers after the Great East Japan Earthquake in 2011. It illustrates both the comparison that was made and the decision about the population to study. The decisions about who to study are set out in the inclusion and exclusion criteria for a trial, which may be broad or narrow, and determine who is and is not eligible for the study *(2).*

### Case Study 4.1.1
### The APOP randomized trial of fish oil for attenuating post-traumatic stress disorder (PTSD) symptoms among rescue workers after the Great East Japan earthquake

The Great East Japan Earthquake and tsunami of 11 March 2011 caused tremendous damage to the north-eastern coast of Japan, leaving 20 000 people dead or missing. Many rescue workers were exposed to traumatic experiences. Researchers decided to investigate whether PTSD symptoms might be attenuated by the use of fish oil. The same researchers had previously shown that PTSD symptoms at 12 weeks after injury were significantly alleviated if patients with physical injury took fish oil. The new study was done among disaster medical assistance team (DMAT) members who were deployed during the acute disaster phase of the earthquake. The randomized trial was approved on 1 April 2011 and started the following day.

After providing informed consent, participants were randomly assigned to one of two groups - one group that received the fish oil supplementation plus psychoeducation, or the other group, which received psychoeducation alone *(3).* The fish oil was given as seven capsules per day, each containing 320mg of fish oil. 172 rescue workers joined the trial between 2 and 12 April 2011 and were followed up over the next few months.

The primary outcome was measured using the Impact of Event Scale-Revised (IES-R), and this showed no significant difference at 12 weeks between the decline in scores for participants in the fish oil group compared to those in the control group *(4).*

In an explanatory trial – also known as an efficacy trial – the inclusion criteria might be kept narrow to ensure that the people recruited to the study are all similar to one another. Such a trial would determine whether, in such ideal circumstances, there is a difference between the interventions being compared. Examples of such studies include: randomized trials to compare the speed of onset of pain control when two formulations of an analgesic drug are used in people with specific types of minor injury; a comparison of surgical techniques for managing fractures of the lower leg; or a test of a psychological therapy in school-aged children following a tsunami. In studies of this kind, the participants would be carefully chosen so that they have the characteristics that are felt to be most receptive to the intervention being tested. One rationale for such trials is that, if the experimental intervention is no better than the routine intervention in these “ideal” circumstances, it is unlikely to be better in a much broader population.

However, in health emergencies and when seeking to manage disaster risk, randomized trials are more likely to take the form of an effectiveness or pragmatic trial. This is because a wide range of participants is likely to be recruited, and there would likely be less strict control over the specific elements of the interventions being tested, in order to make the trial as close as possible to routine practice. In effectiveness studies, the eligibility criteria are broad enough to ensure that many of the types of people who are likely to be considered for the intervention in the future are included.

Such trials might use the "uncertainty principle" to set the eligibility criteria *(5)*, meaning that people would be eligible for a trial if there is sufficient uncertainty about what effects the interventions would have for them. This is also a fair way to allocate interventions when a choice has to be made about who is given or not given the intervention, as is often the case in Health EDRM. When deciding on the eligibility criteria for a trial, and its feasibility, careful consideration is also required of what number of participants will be needed to answer the research question: researchers deal with this when calculating the necessary sample size, which is discussed in Chapter 4.2.

### 4.1.5 Participant selection and informed consent

The success of any prospective study relies on the cooperation of the people who are participating in it. In medicine, one major difference between treating patients inside or outside a research study is the formal process of informed consent that is likely to be required for the study (see Chapter 6.4); this can be challenging in disaster situations where the intervention has to be administered quickly, there is little time to provide detailed information or no opportunity for a full discussion with potential participants. However, there are several examples of ethically acceptable trials conducted in such difficult circumstances. For instance, the CRASH trial recruited patients with serious head injuries and showed that a widely used treatment, steroids, was not beneficial *(6)*.

The uncertainty principle can also be employed in deciding whether or not a trial is ethical (see Chapters 3.4 and 6.4 for a discussion of the ethics of research). For example, it can be used when considering whether it is ethical to not do a randomized trial. If there is uncertainty about the relative effects of two interventions, and both are available and suitable for the target population, the most ethical approach may be for them to enter a randomized trial. This ensures that participants have a fair chance of receiving the more beneficial intervention (since it will be unknown when they join the trial which this will be) and the data collected should help to resolve uncertainty in the future, as was the case with the aforementioned CRASH trial for people with head injuries *(6)*.

### 4.1.6 Randomizing participants

The key feature distinguishing randomized trials from other prospective studies is the use of a random process to determine which of the interventions is received by each participant. This process ensures that any differences between the outcomes for those in the randomized groups will be due either to the effects of the interventions being compared, or to the effects of chance.

Randomization can be achieved in a variety of ways, and some methods are described here. The key elements are the use of a random sequence to allocate participants to one of the groups, and ensuring that no-one knows which group a person will be allocated to before they join the trial. If an individual's allocated group is known in advance, this may lead to a different decision being made about whether they join the trial, or to some other form of manipulation, such as delaying their joining until a different allocation is available.

### Generating a random sequence

In simple randomization, each participant has the same probability of being allocated to each intervention being tested. This can be achieved using simple physical techniques such as flipping a coin, rolling a dice or drawing lots. It might also be done by shuffling envelopes into which information about the allocation has been placed. Mathematical techniques, using random numbers, can also be used. Simple randomization is completely unpredictable, provided that the allocation for an individual participant is concealed up until the point that they enter the trial. However, the disadvantage of simple randomization is that, particularly in a small trial, it can lead to large, chance imbalances between the groups. For example, if a coin is flipped 100 times, it is likely that at some point in the sequence there will be a consecutive run of 6, 7 or 8 heads or tails. If this occurred in a trial, it could lead to an imbalance in the number of people in the groups, making analysis of the trial difficult. It could also lead to imbalances in participant characteristics between the groups, which might also make the analysis of the trial more difficult.

These potential problems can be overcome by using a technique called blocked randomization, which allows stratification of the allocated interventions (or a more complex, computer-based technique called minimization *(7).* Blocked randomization means that after a particular number of participants have been allocated, the numbers in the different intervention groups will be balanced. For example, a block size of four in a trial with two intervention groups guarantees that for each sequence of four people joining the trial, two will be allocated to one group and two to the other group; using that block size for a trial as a whole will therefore ensure that the difference between the number of people in each of the two groups will be no more than two (if, at the start of the final block, two are both allocated to the same group). Similarly, using blocks for different types of people in the trial (for example, young and old, or those living in rural, semi-urban and urban settings) can ensure balance within those groups.

### Concealing the random sequence until the participant joins the trial

Allocation concealment is not the same as blinding or masking the intervention, which is discussed below and happens after the person has entered the trial. Allocation concealment takes place earlier, before the person enters the trial. It means that no-one involved in recruiting potential participants can know what they will receive until they have joined the trial. Allocation concealment prevents manipulation that might arise if knowing the allocation leads to a different decision about someone's eligibility or their willingness to join the trial.

One way to implement adequate allocation concealment is to use sealed, opaque, sequentially numbered envelopes, which must be used in the predetermined sequence and cannot be opened to reveal the allocation until the person has entered the trial. Researchers might also use randomization systems in which an online or computer-based system, or a telephone call, is used to first capture data on the participant before their allocation is given.

### 4.1.7 Blinding or masking

In some studies, it is important that the people involved in conducting the trial do not know which intervention a participant is receiving. This is usually called ‘blinding’ or, particularly when the research is related to eyesight, ‘masking’, and might be achieved by giving patients in the control group a dummy intervention or placebo. However, adding placebos or blinding to trials can be difficult, because doing so increases the resources needed for the trial and can make the interpretation of the results more difficult because after the trial, in routine practice, those receiving or administering an intervention would know what is being taken or given *(8)*.

There are a number of different people involved in a trial who might be kept blind to the intervention and there are a variety of reasons for doing so. Typically, the participant might be kept blind in order to reduce the risk that they will either report outcomes differently because they know which intervention they are receiving or, through a placebo effect, will actually respond differently simply because of their knowledge of the intervention rather than as a result of the intervention itself. Problems can also arise if participants knowing which intervention group they are in makes them change their behaviour in ways that would not happen outside of the trial.

To illustrate the potential impact of blinding: in a randomized trial of an iron-fortified biscuit for children with iron deficiencies, those who know they are in the control group might try to change their eating habits, while those in the intervention group might change in a different way, perhaps assuming that the biscuits will provide the nutrition that they need. Blinding might be achieved by giving those in the control group a biscuit that is identical in every way except for the ingredient being tested, to act as a placebo.

It might also be important to keep people other than the participant blind to the allocated intervention. This can include those treating and caring for patients in a study and the people measuring outcomes. Keeping the practitioners blind ensures that they are less likely to do other things differently for a patient – just as the participant might modify their behaviour if they know which intervention they have been allocated, practitioners might add extra treatments if they know a patient is in the control group or monitor them more carefully if they are receiving the experimental intervention.

Likewise, if the people assessing the participants’ outcomes or collecting data know that someone is receiving the experimental intervention, they might look more closely for side effects. If someone is in the control group, unblinded assessors might be more pessimistic when recording their outcomes. For example, in a trial testing different types of dressing for wounds after surgery, it could be important that the outcome assessor responsible for classifying the level of infection in a wound did not know which dressing was used when they made their assessment. Problems can also arise if the statistician analysing the trial’s results is influenced in how they do this by knowing which group is the experimental group. In such circumstances, it would be important to keep them blind to which group is which.

### 4.1.8 Avoiding publication bias: registering and reporting a study

Even if a researcher is careful to minimize bias when designing and conducting their prospective study, biases can be introduced when they make decisions about reporting its findings. These can lead to problems when the results are used by others. Publication bias arises when the results of a study have an influence over whether it is published. Selective reporting bias can mean that, even though the study is published, some of its findings remain unpublished, while others are given more prominence. Chapter 6.6 describes some of the elements to consider when reporting a research study, and the importance of publishing research in ways that will help people and organizations such as United Nations agencies, NGOs and others involved in Health EDRM to use the findings in their future decision making.

During recent decades, efforts to combat the problems of publication and selective reporting bias have led to the development of prospective registers of research studies *(9).* Registering the study before the first participant is recruited makes the existence of the study public knowledge in a way that ensures that this could not possibly be influenced by its results. It also requires the researcher to say, in advance, what they are studying. Some journals will not publish the results of trials that have not been prospectively registered. Furthermore, in the context of a sudden-onset disaster, carefully pre-planning the trial, registering and perhaps even publishing its full design in advance, allows a trial to be sitting “on the shelf” ready to be activated. Case Study 4.1.2 presents one such example, where a detailed plan has been prepared for a blinded, randomized trial of regional anaesthesia in earthquake survivors with lower limb trauma.

**Case Study 4.1.2**

**Plan for a randomized trial of anaesthesia and pain management for patients with lower limb trauma after an earthquake**

After an earthquake, the largest burden of injuries is due to trauma of the legs and feet, and pain management for these patients is a substantial challenge. The Regional Anaesthesia for Painful Injuries after Disasters (RAPID) trial has been designed to evaluate whether regional anaesthesia, either with or without ultrasound guidance, can reduce pain from earthquake-related lower limb injuries in a disaster setting *(10)*. The plan for the trial was prospectively registered in February 2016.

After informed consent has been obtained, study participants will be randomized in a 1:1:1 allocation to standard care (parenteral morphine at 0.1 mg/kg), standard care plus a landmark-guided fascia iliaca compartment block, or standard care plus an ultrasound-guided femoral nerve block. In order to blind participants and healthcare providers who are not part of the research to a patient's allocated group, sham ultrasound activities will be used in the first two groups and a normal saline injection will be given to the first group (the control group). The primary outcome measure will be a standard pain intensity score over the first 24 hours, with secondary outcome measures including analgesic requirements, adverse events, and participant satisfaction.

If the trial shows that regional anaesthesia is effective in a disaster setting, its future use for survivors of earthquake trauma could reduce both their acute suffering and the long-term complications of the injury.

## 4.1.9 Other types of prospective, comparative study

When it is not feasible to use randomization to allocate individuals to different interventions, there are other methods that can be used. For example, for a research question relating to a comparison of different methods of coordinating the multidimensional response to a disaster, randomly assigning individuals or groups of people to coordinate their actions in very different ways would be likely to lead to chaos. Instead, the new method of coordination could be implemented and then its impact assessed using a "counterfactual" to estimate what might have happened without the intervention in order to decide whether it improved, worsened or made no difference to outcomes. This might also be the case for other interventions; methods for conducting such studies are discussed in Chapter 4.15. To illustrate the planning of such a study, Case Study 4.1.3 describes how the findings from research into a surge of dengue cases at a hospital in Sri Lanka might be used in the evaluation of future changes to hospital strategy and health systems research.

### Case Study 4.1.3
### Planning an evaluation of strategies that would be implemented in a future health emergency

Dengue is the most important infectious disease-related public health concern in Sri Lanka. A massive outbreak occurred at the time of the south-western monsoon rains in 2017: approximately 185 000 dengue cases were reported and more than 400 people died *(11)*. The National Institute of Infectious Diseases, as the leading hospital for managing infectious diseases in Sri Lanka, played a major role during the outbreak and researchers there studied the size and effects of the dengue epidemic *(12)*. Their study identified particular challenges and, along with a systematic review *(13)*, has led to proposals for implementation in the future. These include the need for public health systems to use robust systems approaches with sufficiently detailed managerial approaches. It would not be possible to assess the effects of these systems-level strategies in a randomized trial because it would not be feasible to allocate them to some individuals or hospitals, and not to others. However, it would still be useful to know how effective they are. In order to assess this, a prospective study would be put in place to gather outcome measures that could then be compared with the earlier data. This would seek to answer a research question about whether the new systems were an improvement on the old systems, and provide evidence to inform the decision to continue with them or refine them further for future dengue epidemics. However, caution would be needed when deciding whether the comparison of the future epidemic with that in 2017 was a valid comparison of "like with like" in relation to everything except the new strategies. The prospective study would collect information on the dengue cases, the use of hospital resources and outcomes for patients. It would include attendance at the outpatient department, admissions to hospital and bed occupancy before and during the next outbreak, and demand on services such as the haematology laboratories. These data would then be compared with the findings from 2017, with care being taken to ensure that any differences were not merely due to differences in the way in which the data were gathered.

Two other types of prospective study that might be used when randomized trials are not feasible are described below.

#### Controlled before-after study

In a controlled before-after study, the decision about whether a person will be in the intervention or the control group is not made by the researcher. The outcomes of the people in both groups are measured before and after the intervention is introduced for one of the groups. For example, if some people who lost their homes after a windstorm are given a new type of shelter, their respiratory health would be monitored before and after the delivery of the new shelters, as well as that of a control group of people provided with the usual shelter. One disadvantage of these studies is that they have a high risk of bias because there may be differences between the intervention and control groups. If these differences not only determined whether a person went into the intervention or the control group but also had an effect on their outcomes, it is possible that the study's findings might simply arise from these underlying differences rather than from the effects of the intervention.

**Interrupted time series**
In an interrupted time series design, outcomes are collected at multiple time points, before and after the intervention is introduced. A single setting or group of participants is used, and there is no control group. The effect of the intervention would then be estimated by comparing the trend in the outcomes after its implementation with the trend beforehand. For example, if the level of gender-based violence was holding steady or slowly declining in a displaced person's camp, but declined rapidly after a new strategy was put in place, this would suggest that the new strategy is beneficial. However, a disadvantage of this design is that if any other features of the camp had changed close to the time that the intervention was introduced, it would not be known whether those changes may have caused (in full or in part) any detected improvement (or conversely, if the new intervention did not appear to have an impact, may have cancelled out what would have been a benefit).

## 4.1.10 Conclusions

For many centuries, decisions about interventions and policies intended to improve the health of populations were based mostly on personal experience, anecdotal case histories and comparisons of people who had received one intervention with an entirely separate group who had not received it or had received something different. Although these sources of knowledge are still in use today, they are subject to biases which mean that the information they provide may be unreliable.

In recent decades, routine health care and policy making has relied increasingly on randomized trials and systematic reviews (see Chapter 2.6) of these as a source of reliable and robust estimates of the relative effects of different interventions. Provided the trial is sufficiently large, random allocation ensures that any differences in outcomes between groups must be due to the effects of the interventions. This allows future decision makers to have greater confidence in the answer provided by the trial when they are choosing interventions or setting policy.

## 4.1.11 Key messages

- **People choosing between different interventions, actions and strategies need reliable and robust evidence on their relative effects.**
- **Such evidence needs to come from research that has minimized the effects of bias and chance.**
- **Randomized trials provide a means for testing interventions in such a way that any difference between the outcomes of the participants in the groups being compared are due to the effects of the intervention, or chance.**
- **Pre-planning a trial, or other prospective study, allows it to be ready to be activated when needed, for example in a sudden-onset disaster.**

## 4.1.12 Further reading

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# 4.2

# Measuring the problem: Basic statistics

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## 4.2.1 Learning objectives

To understand the following in the context of Health EDRM:

1. Basic statistical concepts.
2. Epidemiologic study designs.
3. Commonly used sampling methods.
4. Estimation of sample size.

## 4.2.2 Introduction

Statistics are used to describe the health status of population groups, quantify disease burden and estimate the effects of interventions. This is especially important in Health EDRM, where health authorities making decisions about the use of limited resources need to be able to identify the best possible programmes for prevention and care so that they can prioritize key interventions. One of the prerequisites of data analysis is to collect data that will allow the research questions to be answered and hypotheses to be tested (Chapter 3.5). The kind of statistical analyses chosen will depend on the type of data that were collected through research, routine data collection or surveillance data.

Case study 4.2.1 provides an example of how the data collection for statistics was conducted in humanitarian settings.

### Case study 4.2.1
### Measuring the public health problem in a human-made disaster in Sub-Saharan Africa

An armed conflict in Sub-Saharan Africa resulted in a major humanitarian crisis. The conflict internally displaced more than one million people into camps which were largely managed by the United Nations *(1).* Camps for internally displaced persons may have poor living conditions, overcrowding and inadequate access to social services that predispose the displaced populations to outbreaks of infectious diseases such as measles, cholera, malaria, and hepatitis E *(2)*. The Early Warning Alert and Response System (EWARS) was established to address the need for good quality and real-time data for timely detection and response to epidemics in support of the Early Warning Alert and Response Network (EWARN) *(3)*, a system that supports surveillance and response in humanitarian settings where routine systems are unavailable or underperforming *(4).*

The system collects real-time data on infectious diseases, injuries, trauma and nutrition from health facilities managed by frontline health partners in the camps and conflict-affected areas. Data are entered at the facility level and automatically uploaded into a central database. Automated analysis is conducted, a weekly bulletin is generated and disseminated to all health partners on a regular basis. The system resulted in drastic improvements in the timeliness (69%) and completeness (73%) of reporting from the camps and conflict-affected locations and timely detection of several outbreaks including the cholera epidemic of 2016 and measles outbreaks of 2018 to 2019 *(5)*. The system also provides detailed case-based and laboratory data which are used for better characterization and response to outbreaks and for research purposes. Furthermore, the system contributes to improvements in the national Integrated Diseases Surveillance and Response System and has been expanded to generate monthly information on health service functionality and nutrition status. Poor mobile network coverage in the conflict-affected areas of the country remains a key challenge as data are transmitted electronically.

The EWARS has proven to be a good tool in the generation of data for public health decision making during humanitarian crises while also serving as foundation for strengthening disease surveillance during the transition from humanitarian to development programming. The system is also a major repository of secondary research data.

## 4.2.3 Types of quantitative data

The two main types of quantitative data are categorical and continuous. Categorical data can be either dichotomous (taking only one of two possible values) or polytomous (having more than two distinct categories). Dichotomous data are considered binary – for example, vital status might be either alive or dead, a community might have either been exposed or not exposed to a toxic spill and someone might have either received or not received an intervention. Polytomous data have more than two categories and have a number of different attributes. It may be ordinal, being rank-ordered, typically based on a numerical scale that is comprised of a small set of discrete classes or integers, but may not always have a specific set interval between integers (for example, socio-economic status or income level). Alternatively, the categories might not be in any order (for example, types of injury or cause of death).

Continuous data are measured on a continuum and, theoretically at least, can have any numeric value over a continuous range, with the level of granularity dependent on the precision of the measurement instrument. Interval data are a form of continuous data in which equal intervals represent equal differences in the property being measured, for example temperature. Ratio data are another form of continuous data, which have the same properties as interval data, plus a true definition of an absolute zero point – for example weight or height *(6)*.

## 4.2.4 Types of statistical analysis

Statistical methods can be divided into two main branches: descriptive and inferential. Descriptive statistics are commonly used to categorize, display and summarize data; inferential statistics are used to make predictions based on a sample obtained from a population or some large body of information. These inferences can be used to test specific research hypotheses *(7)*. This chapter covers the basic statistical principles that should be considered when choosing a study design and conducting the study. It includes examples and definitions of issues such as summary statistics and the calculation of the sample size needed for a study. Other chapters in this book deal with the development of the research question for a study (Chapter 3.5), study design (Chapter 4.1) and data collection (Chapter 4.4); more advanced statistical techniques are covered in Chapter 4.5.

## 4.2.5 Descriptive statistics

Descriptive statistics are typically used simply to calculate, describe and summarize the collected data in a logical, meaningful, and efficient way. Descriptive statistics do not allow any conclusions to be drawn regarding the validity of research hypotheses. They might include measures of central tendency (such as the mean, the median and the mode) to show the most representative value of the data set. They are usually accompanied by a measure of dispersion (such as the standard deviation or inter-quartile range) to indicate the degree of variation of values within a data set or the level of dispersion of observations around the measure of central tendency. Some of these are described below.

### Measures of central tendency

**Mean:** the mean (sometimes referred to as the arithmetic mean) is the most common measure of central tendency. It is calculated by the dividing the sum total of all observations by the number of records. One advantage of the mean is that, because its calculation includes the summing of all the observations, its value takes into account all the data. However, this characteristic of the mean also makes it especially sensitive to extreme values among the observations, which can skew this central tendency towards extreme outliers. Thus, the mean can be a misleading measure if the data set contains such outliers.

**Median:** this the observation that divides the distribution into two equal parts. In other words, when all observations are ranked from the lowest to the highest, the median is the observation that is located at the half way point. Therefore, the median can only be determined for observations that are ranked by value or size and is less influenced by extreme values. The median can be used to compare groups on certain characteristics (for example, to compare the age between two groups of children or to compare number of days of exposure to extreme weather for people in different regions).

**Mode:** this is the observation or value that appears most frequently in a set of data. The mode is identified by noting the observation that occurs the most or value that has the highest number of records. The mode has the advantage of being easy to identify by simply counting the frequency of the records presenting that value. However, its main disadvantage is its potential lack of stability as a measure of central tendency because it can change if the data set is categorized or even defined in different ways. The mode can be used to determine, for instance, which socioeconomic group has the highest number of individuals.

### Measures of dispersion

**Standard deviation:** this is the square root of the deviance, which is calculated by squaring and summing the difference between each observation and the arithmetic mean. The sum is then divided by the total number of observations. In the same population, the standard deviation is more stable from one sample to another. When comparing two groups or samples, a group or sample with a relatively smaller standard deviation indicates that the members of this group are more homogenous (or similar to each other) than the group with a large standard deviation. If the observations in a data set have a normal distribution, 70% of observations will lie within one standard deviation of the mean and 95% within two standard deviations *(8)*.

**Standard error:** This measures the amount of variance in the sample mean and is calculated by dividing the standard deviation by the square root of the number of observations in the sample. The standard error is used to indicate how well the true population mean is likely to be estimated by the sample mean.

**Range:** This represents the difference between the highest and the lowest values of the distribution and can be used to give complementary information to other statistics, such as the mean. When two distributions seem to have similar means, the range can provide an additional layer of information to distinguish the characteristics of the two distributions.

However, one important disadvantage of the range is that it will be influenced by extreme values. This means that a change in a single record that was the highest or lowest value could have a substantial impact on the range. The range can also be expressed in quartiles or in percentiles to show the highest and lowest values in different parts of the distribution (such as the range of ages for children and for adults in a sample).

**Interquartile range:** Just as for calculating the median as the half-way point in a series of observations, the interquartile range requires the observations to be ranked from the lowest to the highest. The interquartile range median is then the difference between the lower ($25^{th}$ percentile) and the higher ($75^{th}$ percentile) quarters of the observations.

**Confidence interval:** This is derived from the standard error of the mean. The confidence interval (usually 95%) shows the range within which the true population value is likely to fall, based on the sample statistical values and probability data distributions.

## 4.2.6 Inferential statistics

In the context of research into the effects of interventions (as discussed in Chapters 4.1 and 4.3), inferential statistics allow researchers to make a valid estimate of the association between an intervention and its effect in a specific population, based upon their representative sample data. Inferential statistics allow researchers to make generalizations or inferences from the results obtained from the sample to the populations from which the samples were drawn. Approaches to inferential statistics include the estimation of parameters, and the testing of research hypotheses. Inferential statistics vary depending on the type of statistical tests applied in the analysis. For instance, they might use correlation coefficients to assess the correlation and association between risk factors and outcome, or use an odds ratio to measure the probability of an event occurring.

## 4.2.7 Rapid needs assessments

Rapid needs assessments (as also discussed in Chapter 2.1) will usually require basic statistical analyses to be conducted. For instance, in disaster settings, rapid needs assessments often use survey sampling techniques in the field to rapidly determine the health status and basic needs of an affected community. Emergency response requires immediate information on health status and community needs. Such information must be gathered and analysed quickly. In many cases, an assessment may need to be initiated and completed within 72 hours. Speed is critical because circumstances can change dramatically with time, and outdated information may therefore be of little use to response personnel *(9)*. However, these surveys need to be conducted in a statistically robust and valid manner to support decisions about the response. Various areas of consideration (such as disease states or conditions) might need to be measured using various statistical parameters – such as prevalence, incidence and attack rate (see below).

A rapid health needs assessment is often carried out at a single point in time, using a cross-sectional study design. Key stakeholders should be involved in the survey process, and it is important to identify specific targeted groups as the study population, depending on the objective of such needs assessment. For example, when undertaking a nutrition assessment, the study population may include all children under the age of 5 years and their parents. The sample size for the study (see below) might not be estimated statistically but may simply be based on the population who are being studied.

Rapid needs assessments will collect data on the population and may include the number of displaced or affected people and their demographic characteristics (for example, the number of women, men, children, pregnant women and persons with disability). It might also be important to collect data on the proportion of people with shelter, in order to establish the shortfall in shelter requirements for the displaced population (such as refugees or internally displaced persons). Data should also be collected on the available resources (see also Chapter 3.1), including health systems. This might include the number and type of health facilities, number and category of health workers and types of health services available. Depending on the situation, data may also be collected from other sectors such as water and sanitation, education, food security, protection and so on. It might also be gathered to establish a picture of other baseline features, such as numbers of medical staff still working per 1000 people in the population, vaccination rate for key vaccines or rate of severe acute malnutrition. During emergencies, the values of these indicators are usually compared to reference values and norms, such as the Sphere standard to evaluate the status of population humanitarian condition *(10)*. There is more information on health indicators in Chapter 2.2.

## 4.2.8 Epidemiologic Measures

This section provides a brief review of some key terms used in epidemiology to describe data about diseases.

**Population**
In the epidemiology of disasters (Chapter 2.1), the definition of the "population" can vary depending on the situation. In general, the term is used to refer to people living in a defined area, such as a refugee camp, settlement, village or neighbourhood. However, in some situations, it may refer to groups of people being affected by an emergency, who do not necessarily live in a well-defined area. For instance, in an infectious disease outbreak, population may refer to groups of people with a specific characteristic, such as a profession, lifestyle or activity that predisposes them to the disease (for example, farmers, butchers, or those in school settings). It might also be necessary to count subgroups of the population, such as the number of women or the number of children under 5 years of age.

In some cases, the total population figure will be the denominator for calculating health indicators (Chapter 2.2). For example, it might be used to estimate the proportion of people out of the total population who were made homeless after an earthquake, the proportion of pregnant women who are likely to give birth in the days after a disaster, or the proportion of children in an internally displaced person (IDP) camp who have not been vaccinated against measles.

Usually, the census or a registration system might be relied on as the most accurate method of estimating the population. However, in an emergency, it might be necessary to use other methods (Chapter 2.4), such as mapping the IDP camp and dividing it into smaller sections, with the population size of each section estimated using sample surveys.

Depending on the type of data being collected and the context, gathering information from individuals can sometimes be perceived as intrusive. It is, therefore, important to identify and implement methods to count people and cases that maintain the dignity of the individuals involved, using appropriate ethical oversight (Chapter 3.4). This is especially important if public health priorities (speed, accurate information) and human rights priorities (privacy, consent) might come into conflict during data collection.

**Data Analysis**
Basic data analysis can be used to provide information to guide the development and implementation of operational plans for Health EDRM. The information is often summarized into a minimum set related to person, place and time. Minimum data analysis can generate basic answers to questions such as: who is affected or most at risk? Where are those affected or at most risk? What is the trend of the impact of the events on the target population? Subsidiary, basic analysis can provide insight into major risk factors making the target population vulnerable or rendering them resilient to the effect of the hazard. In addition to the descriptive statistics outlined above, epidemiology uses measures of morbidity and mortality and these rely on the quantification of various aspects of health, outlined below.

**Prevalence**
This is useful for understanding the overall burden of a disease on a population, since it describes how common a particular condition is at a given point in time (point prevalence) or the existing and new cases that happen over a set period of time, such as 12 months (period prevalence). Prevalence is a calculation of the existing cases and is determined by the rate of new cases occurring, the rate of recovery and the rate of deaths. Prevalence is often used for conditions that are longer lasting or for which an on-set date may be more difficult to recall (for example, the number of people suffering anxiety related to a disaster).

**Incidence**
This is the number of new cases of the condition occurring in a given population during a defined period of time. There are different ways to calculate incidence, based on the condition, issue or disease. The most common is the cumulative incidence, which is the number of new cases in a specific time period divided by the number of people who were initially disease (or condition) free at the start. For example, if there were 120 new measles cases in one week among 18 000 people in an IDP camp, this would give an incidence rate of 6.7 per 1000 per week. The incidence rate is useful when discussing or comparing acute, communicable diseases of short duration.

**Attack rate**
This is the cumulative incidence rate of a disease in a specified population over a given period of time. It is usually used during epidemics and is calculated as the percentage of the population with a condition out of the

whole population (for instance, those with the condition and healthy, susceptible people) (Table 4.2.1). The attack rate can help when calculating the resources needed to respond to an outbreak. It also provides an idea as to the magnitude of an outbreak in a community or a geographic entity. If immunity to the disease (as a result of vaccination or prior infection for instance) is measured, this may allow some of the population to be removed from the denominator.

**Table 4.2.1 Example of incidence and attack rate for measles among 18 000 refugees**

| Week | New cases per week | Weekly Incidence Rate | Attack Rate |
|---|---|---|---|
| **1** | 120 | 6.7 per 1000 | 0.67% |
| **2** | 150 | 8.3 per 1000 | 1.50% |
| **3** | 80 | 4.4 per 1000 | 1.94% |

### Case fatality rate

This is the number of deaths from a specific disease during the observational period, divided by the number of cases of that disease during that period, multiplied by 100 (to calculate a percentage). The case fatality rate is used mainly in infectious diseases, such as cholera, dysentery, malaria and measles. It provides a useful guide to assess the virulence of the disease, its severity and the effectiveness and quality of care.

### Mid-interval population

This can be estimated by adding together the number of people in the population at the start of the period of observation and the number at the end, and dividing this by two. Alternatively, it can be calculated as the average size of the population during the period. Population data are usually collected from official government census reports or other administrative documents, such as the birth and deaths registry. It may already be available from national statistical offices and published online.

### Benchmarks

These are standards or reference values for indicators that serve as signposts to let the researcher, or other interested people such as policy makers, know what has been achieved or how severe a situation is. They can include key mortality indicators such as the infant mortality rate, cause-specific mortality rate and case fatality rate discussed below.

## 4.2.9 Demographic indices

Demographic indices include statistics such as fertility rates, birth rates, growth rates and mortality rates.

### Crude birth rate

This is calculated as a proportion by dividing the number of live births by the number of people in the mid-interval population, and multiplying the value by 1000 (or other amount depending on the population size) to create a rate.

**Crude growth rate**
This is the crude birth rate minus the crude mortality rate. It provides information on the growth or decline of a population, in the absence of migration.

**Crude mortality rate**
This is calculated as a proportion by dividing the number of deaths at all ages by the number of people in the mid-interval population, and multiplying the value by 1000 (for annual or monthly rates) or 10 000 for daily crude mortality rate. This crude rate does not adjust for the age distribution of the population, and should not be used to compare across different populations.

**Infant mortality rate**
This is calculated by dividing the number of deaths in children under one year of age by the number of live births during the same period and multiplying this by 1000 (or other amounts depending on the population size). Although this is conventionally referred to as a rate, it is really a ratio. This is because in a rate, those counted in the numerator must also be part of the denominator (for example, the number of deaths due to measles divided by cases of measles). However, in the infant mortality rate, some of those children who die during the specified interval (the numerator) might not have been born during the same interval (the denominator).

**Cause-specific mortality rate**
This is the number of deaths from a specific cause during the observational period divided by the number of people in the mid-interval population (or other denominator of the population), multiplied by 100 to provide a percentage.

**Age-specific mortality rate**
Because different populations have different characteristics and age structures it is not meaningful to compare the crude mortality rate for different settings or countries. For example, a high proportion of elderly people in a population will give it a high crude mortality rate and, as a result, the crude mortality rate of the Plurinational State of Bolivia and that of the USA may be very different because of the underlying age-distribution rather than the likelihood of an individual dying. To overcome this, age-specific mortality rates are calculated. There are two different methods of standardizing population statistics – direct standardization and indirect standardization. More information on these methods can found in Gerstmann *(11)*.

## 4.2.10 Epidemiological Studies

Epidemiological studies can be descriptive, analytical or both. Descriptive studies are used to describe exposure and disease in a population (see Chapter 3.2), and can be used to generate hypotheses, but they are not designed to test hypotheses. Analytical studies are designed to test hypotheses, and are designed to evaluate the association between an exposure or intervention and a disease or other health outcome (see Chapters 4.1 and 4.3).

Epidemiological studies can be cross-sectional, prospective or retrospective. A cross-sectional study is taken at a specific point in time. A prospective study is one where the study starts before the exposure and outcomes are measured moving forward in time. A retrospective study is one where the study starts after the exposure has begun and, in some cases, the outcomes have occurred and been measured. It works backwards in time. Epidemiological studies can also be experimental or observational and some of the terminology important for epidemiological studies is described below.

**Exposure**
This is the risk factor (agent, experience or procedure for example) that is suspected to have caused the disease or condition. In statistical terms, exposure is often called the independent variable.

**Outcome**
This is the disease, condition or other endpoint being measured. In statistical terms, the outcome is often called the dependent variable.

## 4.2.11 Descriptive studies

Descriptive studies describe an event, condition or disease state in terms of time, place and person. They include:

- Case series or record review.
- Descriptive incidence study (active surveillance) (for example, collecting information on all cholera cases, by age, sex, location of hut, nearest water source and duration of stay in an IDP camp).
- Descriptive prevalence study (cross-sectional survey) (for example, a study of prevalence of acute malnutrition among children under 5 years of age).
- Ecological study (for example, times series analysis of the impact of air pollution on respiratory morbidity and mortality).

## 4.2.12 Analytical studies

Analytical studies examine the relationship between a possible cause (or exposure or intervention) and its effect (disease or condition). These are generally developed to test a hypothesis, which could have been developed from descriptive studies previously undertaken. Two common examples of analytical studies are cohort studies and case-control studies:

**Cohort study**
In a cohort study, a population is followed over time (either prospectively or retrospectively). There are usually two study groups: those exposed to a certain exposure – which may be either a risk factor (such as diet deficient in vitamin C) or a protective factor (such as measles immunization) – and those not exposed. The cohort study follows both groups over a period of time and estimates incidence of the outcome in each group. The measure of association in this study design is the relative risk, which is the ratio of the incidence of disease in the exposed group to the incidence of disease in the non-exposed group. Cohort studies can be carried out in many time frames, from days to decades.

**Case-control study**
In a case-control study, the two groups being compared are people who meet the criteria (or case definition) of the disease or other outcome and people from the same or similar population who do not, as a control group. This retrospective design is used to determine who was exposed to certain factors (contaminated water, for example) and who was not exposed and whether exposure in those who have the outcome is different to those without. The measure of association in this study design is often the odds ratio, which is the ratio of the odds of disease in the exposed group to the odds of disease in the non-exposed group. The odds of disease is the proportion of people with the disease divided by those without it.

## 4.2.13 Sampling Methods

When choosing the people to include in a study, a variety of sampling methods are available:

**Non-probability or judgemental sampling**
For example – convenience, snowballing or quota sampling.

**Probability sampling**
Probability sampling includes simple random sampling, systematic sampling and cluster sampling; Table 4.2.2 shows the advantages and disadvantages of each of these specific methods.

**Simple random sampling:**
This would lead to a fully random sample by using a method such as a random number table to draw the sample from a whole population to which all the members belong.

**Systematic sampling**
This involves choosing the first member of the sample of the whole population using a random number and choosing the rest of the sample by proceeding at a fixed interval.

**Cluster sampling**
This involves the random selection of a cluster (such as a village, school or hospital) and then random sampling of the individuals from within the selected clusters.

**Table 4.2.2 Advantages and disadvantages of different types of probability sampling**

| Type of probability sampling | Advantages | Disadvantages |
|---|---|---|
| **Simple random sampling** | Minimal bias.<br>Every member has an equal chance of being included (which can balance confounding factors). | Must enumerate all members of the population, which is expensive and sometimes not feasible.<br>Can miss geographical clusters (such as people from a minority ethnic group living in one part of an IDP camp). |
| **Systematic sampling** | Guarantees a broad geographical representation.<br>Do not have to have prior knowledge of the total number of people who could be selected for the study. | May be expensive and time consuming to ensure full randomization. |
| **Cluster sampling** | Easier to conduct, less travel time and cost.<br>Do not need a complete list of the sampling units. | Bias toward more dense areas, such as town centres. |

If a sample is used for a study, rather than the whole population, this leads to an estimate of what the results might be for the population as a whole. If a series of samples is taken, these are likely to give different values, but providing the samples have been selected correctly there should be little variation between them. However, in order to provide an estimate of this variation, confidence intervals are often used to show the extent of the variation. The confidence intervals provide the upper and lower limits of this range. For example, if the mean for a sample was 12% and the standard deviation was 2%, the 95% confidence interval would be shown as 10 to 14%.

## 4.2.14 Sample size calculation

If it were possible for a research study to include the whole population of interest, sampling would not be necessary, but covering a whole population would usually require too much money, time or personnel. Therefore, researchers need to rely on a population subset: the sample. This allows them to seek reasonably valid answers to their research questions, but they first need to estimate the size of the sample needed to achieve this. Determining the appropriate sample size for a study is a fundamental aspect of all research; this is because having an adequately-sized sample ensures that the information the study yields will be reliable, regardless of whether the data ultimately suggest an important difference between the impact of a disaster on different types of people, or the effects of intervention and control in a randomized trial.

Two types of false conclusion may occur when inferences about the whole population are derived from a study of a sample of the population. These are called Type 1 and Type 2 errors, whose probabilities are denoted by the symbols $\sigma$ and $\beta$. A Type 1 error occurs when one concludes that a difference exists between the groups being compared when, in reality, it does not. This is akin to a false positive result. A Type 2 error occurs when one concludes that a difference does not exist when, in reality, a difference does exist, and it is equal to or larger than the effect size defined by the alternative to the null hypothesis *(12)*.

The calculation of a sample size for a research study depends on the type of study being planned, the data to be collected, the outcomes being measured and the hypothesis being tested *(13)*. More information is available in the texts listed in the further reading section (4.2.17) but, in general, sample size estimation depends on the level of confidence and precision. The following formula can be used to calculate the sample size for a binary outcome:

$$n = \frac{Z^2 pq}{d^2}$$

*n* corresponds to the sample size in each of the groups; *Z* is the level of confidence chosen (95% confidence, *Z* = 1.96; 90% confidence: *Z* = 1.68); *g* is the design effect and a usual value for this situation is 2; *p* is expected proportion of the population with the characteristic of interest (such as acute malnutrition), *q* is 1-*p*; and d is the precision (in proportion of one; if 5%, *d* = 0.05).

This formula shows that in order to increase the level of confidence or precision, the sample size must be increased. Therefore, when a study is trying to detect a small effect with high precision (such that the entire width of confidence interval would be consistent with a beneficial effect of an intervention, for example), the study will need to be much larger than when the study is testing a hypotheses that there is a large effect.

## 4.2.15 Conclusions

This chapter presents an introduction to basic statistical concepts, epidemiologic study designs, commonly used sampling methods and estimation of sample size. It provides basic statistical knowledge to support effective Health EDRM.

## 4.2.16 Key messages

- **Statistical analyses of quantitative data from research studies and the results these generate are vital to a variety of types of research in Health EDRM. They help by estimating disease burden (to help with the distribution of humanitarian assistance, for instance), the health consequences of disasters for populations (to help with planning for future needs, for example) and the effects of interventions, actions and strategies (to prioritize the elements to include in humanitarian assistance, for example). They often require the contribution of partners with diverse disciplines.**
- **Practitioners need to understand a variety of methods of data collection and analysis, and apply those most relevant to their research question if they are to answer it reliably. This might include surveys, cohort studies, case control studies or experimental studies such as randomized trials for quantitative research and the use of qualitative methods where appropriate.**
- **Research in emergency settings is constrained by ethical concerns (Chapter 3.4) and limited resources, increasing both the challenges of conducting rigorous epidemiological research and the importance of reliable statistical analysis of the data that are available.**

## 4.2.17 Further reading

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# 4.3 Cluster Randomized Trials

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## 4.3.1 Learning objectives

To understand the role that cluster randomized trials can play in health emergency and disaster risk management (Health EDRM), including:

1. The advantages and disadvantages of the cluster randomized trial methodology.
2. Situations in which cluster randomized trials could be used.
3. Potential difficulties in the implementation of cluster randomized trials and solutions for overcoming them.

## 4.3.2 Introduction

Chapter 4.1 discussed the role of individually randomized trials in resolving uncertainties about the effects of interventions, actions and strategies, and focused on studies in which the allocation to groups is determined at the level of each individual participant. However, in cases where this is not possible or appropriate, studies may be designed to randomize groups of participants ("clusters") rather than individuals, in what are called cluster randomized trials – sometimes also known as group-randomized trials or place-randomized trials – and these are the focus of this chapter.

In a cluster randomized trial, the intervention is directed at a group of people, which makes this design well-adapted for performing research in Health EDRM situations. Common examples of clusters include villages, schools, doctors' offices, and different wards or services of a hospital. A variety of designs have been used *(1)*. For example, cluster randomized trials have been used to evaluate the effectiveness of:

- Mass vaccination *(2)*
- Mass antibiotic prophylaxis during epidemics *(3)*
- Water and sanitation packages designed to prevent diarrhoeal disease *(4–5)*
- Population-based interventions aimed at decreasing the incidence of acute malnutrition *(6)*.

### 4.3.3 Design of cluster randomized trials

Most people are more familiar with individually randomized trials (Chapter 4.1) than with cluster randomized trials. However, many of the same considerations apply to their design. These include:

- ensuring that there is not already evidence that would support the hypothesis being tested (ensuring "equipoise", or genuine uncertainty about the potential effects of an intervention);
- conducting a scoping review (Chapter 3.6) or systematic review (Chapter 2.6) if needed;
- defining relevant outcomes;
- estimating the expected effect size of the intervention;
- developing an appropriate strategy for randomization and, if appropriate and necessary, for blinding participants and others involved in the trial to a person's allocated group.

There are however some important differences between cluster randomized trials and individually randomized trials. For example, the risk of an imbalance in potential confounding factors may be higher in a cluster randomized trial, because the number of clusters included is usually smaller than the number of individuals included in an individually randomized trial. Identifying and mitigating selection bias can also be more difficult in cluster randomized trials, where the study intervention is allocated at cluster level, but some individuals within the clusters may choose not to participate. It is also usually impractical (and often impossible) to keep study participants and researchers blinded to intervention allocation in a cluster randomized trial.

There are several additional considerations specific to the cluster randomized trial design. The first concerns the timing of the interventions in the different groups. Clusters are most commonly randomized in parallel, with group allocation happening at the same time. However, in some cases it is not desirable or feasible to carry out parallel randomization. If an intervention takes a long time to put into place (for example, a sanitary system or a new monitoring system in a hospital ward), researchers will sometimes perform what is called a stepped-wedge cluster randomized trial *(7)*. In this type of trial, the different clusters receive the intervention sequentially, and the outcomes of interest are compared across the different clusters, taking into account when the intervention was implemented, with all clusters having received the intervention by the end of the trial.

Secondly, crossover between individuals in different clusters needs to be minimized. The potential for individuals not in a given cluster to receive the intervention, or to have second-hand or spillover benefit from it, must be considered when designing a cluster randomized trial. If clusters are physically distant and there is little contact between them, significant crossover (or contamination) effects are unlikely. Separation of clusters can be integrated into trial design from the beginning, as was done in a trial of emergency room care for acute stroke in which hospitals were purposefully selected to minimize movement of physicians between emergency departments *(8)*. However, if clusters are contiguous neighbourhoods of a city, or if there are important cultural links between two distinct villages, it is reasonable to expect that some crossover may occur. Researchers should strive to reduce this risk as much as possible.

Thirdly, the effects of clustering need to be accounted for during statistical analysis. In an individually randomized trial, participants receive their intervention (medication, vaccine and so on) and are evaluated individually. In a cluster randomized trial, the intervention is performed at the cluster level, but the outcome of interest is often measured at an individual level. For instance, in a cluster randomized trial evaluating village-level sanitation interventions, where the outcome of interest is diarrhoea, inherent characteristics of the villages, such as socioeconomic level and proximity to a floodplain, might play an important role in the risk of developing diarrhoea. Quantifying the similarities between individuals in a cluster in the intra-cluster correlation coefficient is an essential factor when calculating the sample size and the results of a cluster randomized trial *(9–10)*. Finally, it is important to recognize that inferences made from results of cluster randomized trials are often applied at an individual level, despite the cluster-level randomization. This has important consequences for data analysis, and for communication of trial results. Case Study 4.3.1 describes a novel cluster randomized trial of Ebola vaccines.

**Case Study 4.3.1**
**A novel cluster randomized design for evaluating Ebola vaccines *(2)***

A relatively novel cluster randomized design was used to evaluate experimental vaccines early during the 2014 West Africa Ebola outbreak. The trial was a cluster randomized trial modelled on the ring vaccination approach used in the 1970s to eradicate smallpox. Ring vaccination involves vaccinating individuals who are socially or geographically connected to a confirmed case of an infectious disease, thereby creating a “ring” around infected individuals to prevent spread. In the ring trial, contacts of Ebola cases were enrolled and randomized into two groups, one of which was vaccinated immediately with an experimental vaccine, while the other was assigned to receive the vaccine 21 days after enrolment. The delay of 21 days was based on Ebola’s maximum incubation period of 21 days after infection and on the fact that it takes some time for vaccine-induced protection to develop. The design was chosen because the time delay provided a non-placebo comparator group. Incidence of Ebola was compared between the rings (clusters) vaccinated immediately and those vaccinated with a 21-day delay. This design was controversial among scientists and ethicists, but was seen as an acceptable compromise between scientific rigour and providing hoped-for benefits of an unproven vaccine.

### 4.3.4 Advantages of cluster randomized trials

The most obvious advantage of cluster randomized trials over individually randomized trials is that they allow the evaluation of study interventions that cannot be directed toward selected individuals. This may be because of feasibility (for example, radio advertisements about smoking cessation, or nursing protocols in a hospital ward), or biological mechanisms (such as interventions that aim to induce herd protection in a population). In certain situations, they may also be easier to implement than an individual-level intervention. For example, providing an intervention about hand hygiene to mothers in a rural village would reasonably be expected to have indirect spillover effects to other members of her household *(11)*.

### 4.3.5 Disadvantages of cluster randomized trials

The disadvantages of cluster randomized trials compared with individually randomized trials include the greater complexity of their design, as discussed above, as well as the need to include larger numbers of individual participants to obtain the same statistical power *(11)*. Specifically, the intra-cluster correlation coefficient is the main driver of the differences in sample size and clustering must also be considered during analysis of trial data. An example would be an educational intervention in which schools are randomized to one of several new teaching methods. When comparing differences in outcome achieved under the new methods, researchers must account for the fact that two students sampled from the same school are more likely to be similar in terms of outcomes than two students sampled from different schools. Multilevel or other similar statistical models are typically used to correct for non-independence of this kind.

On a more practical level, the hierarchical nature of cluster randomized trials can lead to a duplication of upstream preparation and sensitization efforts – first at cluster-level, and then among individuals in the clusters. This may have cost and time implications for researchers.

Cluster randomized trials are generally not designed to show individual-level effectiveness as a primary objective because the interventions happen at population level. For this reason, it is unusual to use a cluster randomized design with non-licensed products. Nonetheless, in some cases, it is possible to estimate individual effectiveness of an intervention by comparing outcomes among persons who are known to have received the intervention with those who are known not to have received it.

### 4.3.6 When to use a cluster randomized trial design

Cluster randomized trials are best suited for testing interventions intended for a group of people. Any population-based, mass distribution or administrative activity, such as those used in Health EDRM, lends itself well to cluster-based randomization. Health promotion activities and other interventions aiming to change behaviour are often tested in cluster randomized trials. This is also the case for interventions with a high risk of contamination. In this context, the term “contamination” refers to when individuals randomized to different comparison groups are in frequent contact with one another and thus may be influenced (contaminated), in either or both directions. Contamination is likely to occur in comparisons of interventions within the same community, but randomizing at community-level is an effective solution to this problem.

Cluster designs can also have practical advantages over individual randomization. They are easier to understand conceptually for policymakers who may be less familiar with the statistical and scientific properties of different trial designs, because they mirror more closely how interventions are implemented at scale. This is one of the reasons they are also a design that should be considered in an emergency, disaster or public health crisis. The design provides easy-to-understand information for groups of people and policy-makers, and can reach more participants due to the larger sample size. It is also important to consider that cluster randomization can capture both direct and indirect effects of an intervention. This is important when assessing effectiveness in a population and means that cluster randomized trials are well-suited to infectious diseases, when there might be direct benefits to those who receive the intervention as well as indirect benefits to those around them, who may benefit from a reduction in exposure *(12)*.

Case Study 4.3.2 describes how a cluster randomized trial was used to test village-wide antibiotic prophylaxis for meningococcal meningitis.

### Case Study 4.3.2

### Testing a strategy of village-wide antibiotic prophylaxis during a meningococcal meningitis outbreak *(3)*

Mass vaccination campaigns have been part of the standard response to meningococcal meningitis outbreaks in the African meningitis belt for decades, but vaccine supply is not always guaranteed. Antibiotic prophylaxis for contacts of cases is recommended in high-income countries but is not recommended in the meningitis belt because of a lack of evidence. As meningitis epidemics are seasonal, a cluster randomized trial protocol was prepared to test whether a village-wide prophylaxis strategy would work in this setting. When an epidemic hit the Madarounfa District of the Republic of the Niger, the trial started. After the first case was notified in each village, that village was randomized to receive either no prophylaxis, prophylaxis with single-dose ciprofloxacin for household contacts of meningitis, or a village-wide distribution of single-dose ciprofloxacin. The primary outcome was overall meningitis attack rate in the villages at the end of the epidemic. Household prophylaxis did not reduce attack rates, but village-wide prophylaxis reduced attack rates by 60%.

This trial is an example of research performed in an emergency setting. Not all emergencies can be predicted in advance, but in this setting, it was reasonable to be prepared for a meningitis epidemic. The advance preparation, including ethical review, meant that the trial could start very quickly after the beginning of the epidemic. A cluster randomized design was appropriate because the village-wide distributions were implemented across an entire population. Clustering within the individual villages was weaker than expected, which allowed for greater statistical power to discern differences in the meningitis attack rate. Because the villages included in the trial had a reasonable degree of separation, there was little evidence of spillover, which added to the reliability of the main results. If the villages had been closer to each other or there had been more social contact between them, it is likely that more persons from villages randomized to no prophylaxis or household-prophylaxis would have received prophylaxis, which could have influenced the results.

### 4.3.7 Informed consent in cluster randomized trials

Ethical issues relating to informed consent for participation in research are discussed more fully in Chapters 3.4 and 6.4. In an individually randomized trial (Chapter 4.1), a researcher approaches a potential study participant, explains the nature of the study, potential harms and benefits of participation, and underscores the potential participant's freedom to choose whether to participate in the study without negative consequence. If the participant provides informed consent, they are randomized and receive the study intervention and follow study procedures.

However, this procedure can be difficult – or even impossible – to replicate in cluster randomized trials, which generally take place at a larger scale, and in which many participants will not directly receive the study intervention which is to be given at the cluster level. Researchers and ethicists have therefore established a set of guidelines for the ethical conduct of cluster randomized trials, including issues related to obtaining informed consent from participants: the Ottawa Statement on the Ethical Design and Conduct of Cluster Randomized Trials *(13)*.

The guidelines require that trial protocols be reviewed by ethics committees, and address some of the inherent challenges with trials where the level of intervention (cluster level) may differ from the level of outcome ascertainment (individual level). All individuals living in participating clusters are considered to be research participants, which may prove problematic given the size of some cluster randomized trials. Crucially, the guidelines lay out specific criteria for justifying the use of "gatekeepers" who may provide permission for a cluster to participate in a trial (such as a village chief or a nurse manager of a hospital ward). The permission of a gatekeeper should not be confused with proxy consent for individuals to participate, but does allow for most cluster randomized trial interventions to proceed without the individual-level informed consent that is required in individually randomized trials.

Nonetheless, even if a gatekeeper provides permission to participate, researchers have an obligation to communicate openly with individuals in the randomized clusters about the objectives of the research, their individual risks and benefits, and their autonomy to decide whether to participate in study activities, including simply being counted as a study participant. The Ottawa Statement is very clear that any derogation of individual consent must be reviewed and approved by ethical review committees (Case Study 4.3.3).

If unlicensed or investigational medicines or vaccines are used in a cluster randomized trial, it is likely that individual written informed consent would be required from all participants, just as in an individually randomized trial. Given the comparatively larger size of most cluster randomized trials, researchers should consider this during trial design and when they are planning the number of staff that they will need.

### Case Study 4.3.3
### Permission to participate and informed consent process in a cluster randomized trial

In the antibiotic prophylaxis trial described in Case Study 4.3.2, 49 villages were included in the trial over the course of only 27 days. The total population of these villages was 71 308, including 22 177 who lived in villages that were randomized to receive village-wide distributions of antibiotic prophylaxis.

Even without the emergency situation caused by the ongoing epidemic, it would have been impossible to obtain individual written consent from all persons living in the randomized villages over that brief time period. During study protocol development, the researchers reviewed the Ottawa Statement, and after consultation with the ethical review committees, determined that the criteria for the waiver of individual consent were met. During the trial, village chiefs served as “gatekeepers” and were asked to provide permission for the randomization of their villages.

At the same time, community health workers shared information about the trial in all participating villages. In villages allocated to receive ciprofloxacin distributions, the same community health workers passed through the village before the distribution to give information about the potential harms and benefits of single-dose ciprofloxacin prophylaxis and underscored that there was no obligation to take the prophylaxis. During the village-wide distributions, 77% of the target population received ciprofloxacin. The researchers believed that this was partly due to absences and partly due to individuals choosing not to participate, suggesting that the overall informed consent process of the trial was successful.

## 4.3.8 Special design and analysis considerations

Cluster randomized trials require careful reflection during their design and analysis. This is primarily because data collected about individuals in clusters are almost always correlated. The outcomes of an individual within a cluster may be likely to be the same as that of other individuals in the same cluster. This needs to be accounted for in the analyses, and subsequent interpretation of the results must consider both intra-cluster correlation and between-cluster variability. Between-cluster variability can be summarized using the coefficient of variation between clusters, and the intra-cluster correlation coefficient. These intuitive statistical properties require the guidance of a researcher experienced in these techniques who can help guide the design of the trial.

## 4.3.9 Conclusions

Cluster randomized trials have become more common and have been implemented for a variety of Health EDRM issues. Although they are similar to individually randomized trials, cluster randomized trials have important design differences that have implications for data analysis and interpretation of results.

## 4.3.10 Key messages

- **Cluster randomized trials are interventional studies well-adapted for many emergency situations, and are ideal for evaluating population-level interventions.**
- **Compared to individually randomized trials, cluster randomized trials usually require larger numbers of participants and can be more complex to design and analyse.**
- **Cluster randomized trials can be parallel randomized or sequentially randomized, such as in a stepped-wedge design *(7).***
- **The fundamental ethical principles are similar to those in individually randomized trials, but the Ottawa guidelines consider the particularities of cluster randomized trials** *(13)***.**
- **Design and analysis of cluster randomized trials requires careful reflection and the guidance of experienced researchers.**

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# 4.4

# Collection and management of good quality data

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## 4.4.1 Learning objectives

To understand key aspects of data collection for research in health emergency and disaster risk management (Health EDRM), including:

1. Different sources and methods for data collection, along with their advantages and limitations.
2. Challenges involved in collecting data in disaster settings, and how these might be overcome.
3. The importance of data quality, data storage and data sharing.

## 4.4.2 Introduction

The timely collection of good quality data on key aspects relevant to disaster risk management, including emergency response is critical to Health EDRM research, as research outcomes are dependent on data quality and outputs. High quality research and data are invaluable to enable:

- Planners and responders to implement Health EDRM for effective and efficient action in the areas where their work is most needed.
- Policymakers to influence evidence informed best policy and practice in Health EDRM.

Good quality research requires data that are relevant to the research question and objectives, which may include demography, morbidity, mortality, infrastructure, different health factors, environmental characteristics, and so on. Such data are needed to manage disaster risk so that future disasters can be avoided or their impact minimized. It also supports the planning, management, and evaluation of post-disaster interventions. Poor quality data will lead to poor quality research and, potentially, to misinformed policies. Therefore, it is key to ensure the collection of high-quality data during any study.

This chapter discusses important aspects that should be considered before, during and after the process of data collection in order to ensure that good quality data are used and available in disaster research. It explores the planning and preparation processes, different methods for data collection, as well as the challenges that a researcher may face when studying disasters and tools that might help them to address these challenges. Finally, it will discuss how to ensure good quality data are stored and made accessible to others so that it can bring additional benefits.

## 4.4.3 Preparation

Successful data collection demands careful preparation. It is important to formulate a clear and specific research question or hypothesis to be tested, and then to plan what specific data and what collection strategy will provide adequate and sufficient information to answer that question or allow the hypothesis to be accepted or rejected. Although it can be tempting to adapt the data collection or methods of an ongoing study to collect additional data to test another hypothesis, without proper reflection and planning, this can result in the presence of confounding factors in the collected data, leading to biased results. Alternatively, it can also compromise the statistical power of the results. Having a clear research question and aim at the start of the planning process can help to avoid such issues (Chapter 3.5).

It is also important to have a clear, written protocol before data collection begins, and this may be needed when seeking ethics approval (Chapter 6.4). This includes the research question, aim and objectives, definitions of exposure, outcome, and other terms, the expected sample size, the methods to be used, how participants will be recruited and how the data will be curated and analysed after collection. Furthermore, agreement on clear hazard definitions is key to allow comparability on data collected from different sources. Conducting a literature or scoping review before you write your protocol is an important tool to understand how other researchers studying disasters and disaster risk management have collected data on similar contexts, or how they answered similar questions (Chapters 2.6 and 3.6). This can help in the understanding of what strategies work best, as well as with anticipating the main challenges as encountered by others, so that the researcher is prepared to deal with these should they appear during their study.

## 4.4.4 Data collection methods

Once a research question and the variables of interest have been defined, the next step is to determine how these parameters will be measured. Depending on factors such as the study design, funding, time and human resources available, the researcher may decide between collecting new data or studying data that have been previously collected by others. These different approaches are also known as primary and secondary data collection methods.

## 4.4.5 Primary data

Primary data are data collected for the first time and for the purpose of a specific study. The researchers conducting that study decide where, how and when the data will be collected to specifically address their research question. However, this approach can be expensive and time consuming, and may demand technical resources. Methods of primary data collection can be broadly divided into two approaches:

**Quantitative methods** are used for numerical data. They include analysis of the data using descriptive and comparative statistical techniques (see Chapters 4.2 and 4.5) to answer specific questions about, for example, how commonly something occurs, or differences between groups. In Health EDRM, this approach can be used to estimate morbidity and mortality. It can also be used in the construction of more complex models to estimate, for example, the economic impact of a flooding in an affected area (Chapters 4.6 and 4.7). Data collection methods in quantitative research can involve surveys (Chapter 3.1), the measurement of outcomes in experiments or observational studies (Section 2 and Chapter 4.1), and the use of routinely collected data from different monitoring systems (Chapter 2.4). It usually requires large sample sizes and appropriate sampling of the participants from whom the data will be collected, in order to ensure the desired generalizability of the results.

**Qualitative methods,** which are discussed in detail in Chapter 4.12, are most often used to study research questions about how and why phenomena occur, and use observed and recorded non-numerical data, such as words and images, to understand meaning. The collection of such data is usually performed through in-depth interviews, focus groups, key-informant interviews, and observations. Because statistical methods are not used for qualitative research, there is no predetermined sample size. A qualitative approach is particularly useful when the objective is to understand underlying reasons, opinions and motivations during exploratory research, or to develop a theory. For example, it can be employed during a study that aims to understand the drivers of behaviour change related to the implementation of safe burial practices during an Ebola outbreak. It is also useful in the development of hypothesis to be tested in later quantitative studies.

## 4.4.6 Secondary data

Secondary data comprises data already collected or produced by others. Common sources of secondary data are government databases and publications, books, scientific papers, media channels and routine data. Routine data are data collected in a periodic, systematic manner by the government or other organizations (Chapter 2.4) and include:

- **Demographic data**, describing variables such as age, sex, ethnicity, migration patterns, marital status, and so on.
- **Health event data**, describing health variables that affect individuals or populations, including births, deaths, and population interaction with the health sector at different levels.
- **Circumstantial data**, describing factors associated with the social determinants of health, including data on education, employment, housing and environmental data.

- **National reference data**, which covers data that has not been issued purely for health purposes, but when integrated and combined with other variables can be useful in the understanding of different health issues.

Using secondary data means the researchers do not have full control over data quality, making it more difficult to ensure that the dataset they use is complete, unbiased, time accurate, and reliable. Table 4.4.1 highlights important key points on data quality that must be considered when using secondary data.

**Table 4.4.1 Important considerations for the use of routine data *(1)***

**Accuracy:** to what extent is the dataset accurate? What are the potential biases?

**Precision:** Have appropriate measures of uncertainty been included (such as 95% confidence intervals)?

**Completeness:** how much of the data is missing?

**Timeliness:** were the data collected in a period that is relevant to the study?

**Coverage:** is the whole population of interest covered? If not, how does this impact the study?

**Accessibility:** who has access to the data, and how is this access controlled?

**Confidentiality:** have individual-level data been anonymized?

**Original purpose of collection:** can the data be used for a different purpose to the one for which it was collected? Who collected the data and how?

**Analysis:** have the data been standardized and presented in a comparable way?

## 4.4.7 Dealing with challenges in disaster data collection

Researchers can anticipate facing different challenges during data collection. Some examples are:

- limited access to certain areas due to infrastructural collapse (destruction of roads and other transportation systems, for example).
- Persistence of the hazard that originated the disaster, which might pose a risk for the research team (radiation after nuclear incidents, for example).
- emergence of infectious diseases outbreaks due to damaged or poorly functioning water and sanitation infrastructure, which can become a threat to the local community and researchers (cholera epidemics after floods, for example).
- political barriers (local authorities attempt to minimize or change disaster-related statistics, such as mortality estimates, or refuse access to the planned research site, for example).
- language barriers, when the researchers do not speak the local language, leading to the possibility of bias in the use of translators.

Case Study 4.4.1 illustrates how researchers in the field can face some of these barriers. The early consideration of the challenges that are most likely to be encountered can help choosing the most appropriate data collection strategy.

### Case Study 4.4.1
### Challenges in disaster data collection after the 2004 Indian Ocean Earthquake and Tsunami *(2)*

The 2004 earthquake and tsunami that occurred in the Indian Ocean affected 12 countries and left almost 230 000 people dead and approximately 1.7 million people displaced *(3)*. In the post-disaster environment, different groups conducted research aiming to understand how the event affected factors such as the health status of the local communities and their health needs. These groups faced various challenges in data collection.

For example, a study was conducted to determine the public health impact of the tsunami on the population of three communities in Aceh Jaya District, Republic of Indonesia. However, all health facilities in the three communities were destroyed during the tsunami, and the only health professionals to survive the disaster were two midwives. As a result, much of the data had to be obtained from secondary sources, such as reports from local authorities, and the results of the study were thus susceptible to recall, reporting and misclassification biases *(4)*. Another study found that poor health record keeping in facilities prior to the tsunami limited the comparative effectiveness of the health data collected after the tsunami. This led to issues in determining which health-related issues were the result of the disaster and which reflected pre-existing problems *(5)*.

In another study, the French Army medical service carried out an epidemiological survey to estimate health indicators in children during the weeks following the tsunami in Meulaboh. They reported issues with communication and translation during interviews, where sometimes it was difficult to communicate directly with the children or their parents, leading to errors of interpretation. Furthermore, the researchers also faced barriers related to the transportation of the data collection teams among the disaster settings *(6)*.

There are different approaches that can support researchers in gathering good quality data and overcoming the challenges involved in data collection for disaster research. The use of routine data, for example, is a useful tool in contexts where time and resources are constrained (Chapter 2.4). For example, using secondary, routine data can rapidly provide the necessary information to compare before and after disaster scenarios, demonstrate change in demand for specific healthcare services, and to evaluate its impact on local health systems, as demonstrated by Case Study 4.4.2.

### Case Study 4.4.2

### An ecologic study to evaluate the impact of the 2011 Rio de Janeiro landslides in the utilization of public mental health services *(7)*

Many areas of the south and south-eastern regions of Brazil are hit frequently by heavy rains during the summer months. These regions have some of the places with the highest population density in the country and many people living in disaster-prone areas. This leads to important vulnerabilities and thus many communities are under extensive disaster risk of landslides and floods. The 2011 landslides in the mountainous region of Rio de Janeiro State were the largest disaster by immediate death count in recent Brazilian history, with a report counting 845 immediate deaths, mostly by mud burial. Moreover, around 30 000 people were left homeless in 11 different municipalities and there was important damage to agricultural and industrial activities.

An ecologic study was performed using routine data from DATASUS (Departamento de Informática do SUS - Informatics Department of the Brazilian Public Health System in free translation). DATASUS comprises a wide range of open access data, and allows researchers to gather and analyse datasets regarding health outcomes, the incidence of diseases and on the utilization of the health services in different levels.

The study analysed data from the affected region of Rio de Janeiro state two years before and after the event and comparing it with unaffected regions of the state. The analysis of the data suggested a sustained increase in the search for mental health services by the affected population after the landslides, which was not found in the other regions of the state.

The use of routine data can also be helpful in the construction of models to leverage disaster risk reduction strategies. Case Study 4.4.3 presents an example where this approach was used to better prevent and respond to infectious diseases outbreaks.

### Case Study 4.4.3
### The combination of cholera outbreak data and satellite environmental information to estimate cholera risk *(8)*

Cholera is an infectious disease caused by the ingestion of contaminated water or food with the bacteria *Vibrio cholerae*. Water-related diarrheal diseases like cholera are estimated to kill approximately 1.5 million people every year. They are the second leading cause of death in children under five years old. The impact of cholera is higher in settings with poor availability of clean water, as well as places susceptible to floods and with heavy rainy seasons.

Scientists combined in an algorithm data related to the time and location of previous cholera outbreaks in sub-Saharan Africa with different satellite datasets, including precipitation, air temperature, and land surface temperature. The algorithm was tested in five cholera epidemic regions of Sub-Saharan Africa (Mozambique, Central African Republic, Republic of Cameroon, South Sudan, and Republic of Rwanda), and was able to identify and predict regions most at risk for an outbreak at least four weeks in advance *(8)*.

In the Republic of Yemen, this model has been used to predict where and when the next increase in cases of cholera will happen. When risk areas are identified, local partners can work in managing disaster risk by directing emergency resources to the most critical areas, improving infrastructure where needed, chlorinating water and running educational and vaccination campaigns *(9–10)*.

To build a complete picture related to the hazard or disaster of interest, information from several data sources are likely to be needed. It is also important to note that, in different countries and contexts, the data of interest may be collected and curated by different organizations, which can include the Ministry of Health, National Statistics Offices, or even be fragmented through different levels of regional and local health departments (Chapter 2.4). This can result in extra time and resources needed to collect and standardise data provided by different sources.

However, in settings where local data collection for relevant parameters is poor or absent, the use of secondary data might be constrained. Depending on the availability of time and resources, you might choose to perform the primary data collection yourself using protocols with relevant ethical consent (Chapters 3.4 and 6.4). If this is not suitable to your context, the development of models can also be considered as an alternative strategy to fill the information gaps (Chapter 4.6). This can be an important opportunity to raise awareness among local governments, universities and independent organizations about the importance of initiating and maintaining good routine data collection and how this might help them prevent and respond to disasters.

### 4.4.8 Different approaches in data collection

There are a growing number of useful tools to support disaster research, and big data can be leveraged to provide important information in a variety of contexts. Big data includes data such as satellite imagery, images and videos from unmanned aerial vehicles (UAVs), sensor web and Internet of Things (IoT), airborne and terrestrial Light Detection and Ranging (LiDAR), simulation, crowdsourced information, social media, and mobile global positioning system (GPS) and Call Data Records (CDR) *(11).*

For example, the management of disaster risk can be supported through images and videos captured by satellites or UAVs to develop hazards maps and risk assessments. Similarly, the assessment of post-disaster damage through change detection, for instance, provides enhanced situational awareness, supporting and guiding action from rescue teams. It may also be possible to use crowdsourcing to gather these types of data (Chapter 5.2).

### 4.4.9 Data storage and data sharing

When the data has been collected and cleaned, the next step is to store it securely for current and future analysis, and to consider how it might be shared so that others can also benefit from it.

According to the type of research study, it is possible that data will be collected from multiple sources. Therefore, the design of a curation system should account for such differences and allow standardization. This can be achieved by a computerized database with clear rules for data entry. This involves facilitating the user role by requiring only the needed information to be added. For example, for discretionary variables, the adoption of drop down lists to be selected by the user instead of empty spaces for free text can help reducing entry errors and ensure standardization. Similarly, the implementation of rules such as limiting the valid range for variable fields and flagging errors if information is not adequately entered in a core field exemplify how the adoption of simple, good practices, help the achievement of a complete and accurate dataset *(12)*.

It is also important to consider that the usefulness of a dataset to others can be enhanced by providing data as disaggregated as possible, but while still safeguarding individual privacy. A simple example to understand this principle is when reporting on residents who have been affected by a local flood, a dataset which can be filtered according to sex, age, socioeconomical factors, health status and disability allows a much broader set of analysis to be made, such as developing hypothesis on the correlation of the outcome with possible risk factors. The more disaggregated a dataset can be to the individual level, the more invisible persons can be made visible. It can then be used as reliable evidence to inform policymaking, for example helping to direct resources to those affected who need it the most.

There is currently a widespread call across research for making data open and transparent, improving its usefulness so that others can also benefit from it. The 'data revolution' comprises the large increase in the volume and types of data that are currently collected by governments, private companies, NGOs, researchers and citizens. This is leading to an unprecedented possibility of transforming such data into knowledge to not only manage disaster risk but also to better respond to disasters *(13)*. However, important data are often not released rapidly, or not shared at all, which compromises the potential re-usability of many datasets. The FAIR principles of data sharing were developed to assist in the production of good-quality data, with practical actions that can be adopted to increase findability, accessibility, interoperability and reusability of datasets *(14)*.

Examples of actions that can improve data quality and interoperability include the use of clear standards and definitions, as well as the use of data dictionaries to describe the variables and values present in a given dataset. A challenge faced by Health EDRM researchers is the great variety of hazards and the lack of agreed definitions on them. Different definitions for a given hazard hampers the comparability of results from different studies, for example. As a result, it is important to have clear case and hazards definitions when conducting research in emergencies and disasters, and to present data in a machine-readable format, so that it can be retrieved and processed by computers.

### 4.4.10 Conclusions

Overall, data collection in the context of disasters is a challenging task that demands careful preparation and planning. Different methods can be used to gather data, and the local context, time and resources available should be considered in selecting the most suitable approach for a specific study. Science-based policy making depends on high quality research, which in turn is dependent on high quality data. Therefore, it is important to ensure that data are collected, stored and shared at high standards. A careful preparation is essential to achieve this, including the construction of a research protocol containing a clear and specific research question, objectives, the strategy to be used during data collection and how the data will be curated and analysed at a later stage.

### 4.4.11 Key messages

- **A specific research question and a data collection strategy that will provide adequate and sufficient information to answer this with the available resources are important for high quality research.**
- **It is fundamental to acknowledge that despite good preparation, challenges may occur. Anticipating how to deal with them can help researchers to overcome future barriers.**
- **A careful plan on how the collected data will be stored and shared in the long term will ensure that others benefit from the study.**

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# 4.5

# Advanced statistical techniques

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## 4.5.1 Learning objectives

To understand the following more advanced factors to consider in developing an impact evaluation for health emergency and disaster risk management (Health EDRM):

1. Different approaches to estimating impact in the absence of random assignment.
2. Advantages and disadvantages of these different approaches.
3. Importance of baseline data for both intervention and comparison groups.

## 4.5.2 Introduction

Random assignment usually provides the most robust method for comparing the effectiveness of interventions (Chapter 4.1). However, it may not be possible in some settings related to Health EDRM. For example, the implementing agency might not be willing to accept randomization, or the impact evaluation may have to be designed after an intervention is already underway or even completed. When randomization is not possible, impact can still be estimated through a range of non-experimental techniques, which may be broadly divided into two categories: quasi-experimental methods (see also Chapters 4.14 and 4.15) and regression-based approaches.

Quasi-experimental (QE) methods identify a comparison group using statistical matching, such as propensity score matching and coarsened exact matching. Matching is also used to increase the power of designs such as difference in differences, which are explained below. Matching ensures that the comparison group is as similar to the intervention group as possible, such that the average characteristics (age, location and education, for example) of the intervention and control groups are similar at baseline (that is, pre-intervention). Impact is then calculated as either the difference in outcomes after the intervention (ex-post single difference) or the difference in the change in outcomes between baseline and endline (difference-in-differences).

Regression-based approaches include instrumental variables, Heckman sample selection models, endogenous switching regressions and fixed effects models. These approaches require the use of data in untreated or less treated units. Endogenous switching models and Heckman selection models are not covered in this chapter, and information on them is available elsewhere *(1)*. Regression based approaches are usually the only option if the intervention is measured as a continuous indicator (for example changes in the amount of exposure to the intervention), rather than as a binary indicator (that is, the intervention is either provided or not provided).

Non-experimental approaches are best based on specifying the underlying structural model, that is the set of behavioural relationships which lead to intervention impact (see Chapter 4.10). Applying non-experimental approaches requires data from both an intervention and a comparison population. Moreover, more reliable impact estimates are usually possible if baseline data are available that provide variables for matching that are unaffected by the intervention, since such data were collected before the intervention took place.

This chapter introduces three common matching techniques: propensity score matching, regression discontinuity and interrupted time series, as well as one regression-based approach: instrumental variable estimation. First, the following section explains how impact can be estimated using differencing.

## 4.5.3 Double difference estimates

When the intervention has taken place, impact can be estimated by single or double difference. Table 4.5.1 shows the different stages of an intervention (top row) and the data that are required to apply these approaches.

**Table 4.5.1 Timing of intervention and surveys for large impact evaluations**

| Start of intervention | During intervention | At end of intervention | After intervention |
|---|---|---|---|
| B: Baseline | M: Mid-term | E: Endline | P: Post-endline |

**Description**
Ex-post single difference impact estimators are calculated as the difference between the outcome indicator after the intervention (that is, at endline, time E) in the intervention group and the outcome indicator in the comparison group which did not receive the intervention. The double difference impact estimate is the difference in the change in the outcome indicator for the intervention and for the comparison groups between baseline and endline, rather than the difference in their endline values, as is the case for the single difference. Double differencing removes any difference in the indicator between intervention and comparison groups that was present at baseline. This is useful because these baseline differences cannot be a result of the intervention. If the values of the outcome indicators for the intervention and the comparison groups are the same at baseline, then the single and double difference estimates are equivalent.

Double differencing is a means of calculating the estimated impact. It is also used as an impact evaluation method. Double difference estimates require baseline data that should be collected immediately prior to the intervention. The validity of this approach relies on the 'parallel trends assumption', that is, the trend in the outcome in intervention and comparison populations should be the same without the intervention. The parallel trends assumption can be tested *(2)* if trend data from before the intervention are available, but unfortunately this is often not the case. Acquiring more data points (observations) before and after the intervention allows a visual inspection of whether the parallel trend assumption holds. If the assumption can be tested and does not hold, then using double differencing without matching cannot be expected to be free of bias. Matching can help to control for observable determinants of differences in changes over time and make the analysis less dependent on this assumption. Implementation of the method requires data on outcomes from the intervention and comparison groups at baseline and endline. If matching is to be used, then data for matching are also required.

**Advantages and disadvantages of double differencing**
Double differencing is easy to implement and easy to understand. However, pre-intervention trend data may not be available to test its validity. Hence, it is more rigorous when used with a matching technique.

### 4.5.4 Propensity score matching

Propensity score matching (PSM) creates a comparison group from observations on a population that did not receive the intervention by matching intervention observations to one or more observations from the sample without the intervention, based on observable characteristics. Matching is based on the propensity score, which is the estimated probability of being in the intervention group given the observable characteristics. The propensity score is estimated using a regression model of participation (taking part in the intervention). Propensity score matching cannot incorporate selection on unobservables, so may give biased estimates if these are important. Additional information is available elsewhere *(3–5)*.

**Description**
Perfect matching would require matching each individual or unit in the intervention group with a person or unit in the comparison group that is identical on all relevant observable characteristics (for example, age, education, religion, occupation, wealth, attitudes to risk and so on). Clearly, this is not possible nor is it necessary. 'Balance' between intervention and comparison group units (which is necessary for unbiased estimates) requires that the average characteristics of the intervention and comparison groups are the same before the intervention. A good example on the methods used for variable selection in PSM is provided by Brookhart and colleagues *(6)*.

In PSM, matching is not achieved on every single characteristic but on a single number: the propensity score. This is the likelihood of a person taking part in the intervention given their observable characteristics. This probability is obtained from the 'participation equation': a probit or logit regression in which the dependent variable is dichotomous, taking the value of 1 for those who took part in the intervention and 0 for those who did not. The right-hand side of the equation includes all observed variables (individual, household or firm and community or market) that may affect participation, but that are not affected by the intervention. Baseline values of all variables, including outcomes, cannot be affected by the intervention, so having baseline data helps to obtain a stronger match.

Observations outside the ‘region of common support’ are discarded before matching. The region of common support is the area of overlapping propensity scores. Therefore, those observations with very low scores (which typically come from the comparison group) or very high scores (typically from the intervention group) are discarded. The observations retained from those who did not receive the intervention are used as the comparison group, which ensures that the comparison is ‘like with like’.

Each member of the intervention group is matched to one or more members of the comparison group. This is done through a variety of matching algorithms such as the nearest neighbour matching, caliper matching and kernel matching. An example is the study by Boscarino and colleagues *(7)* which uses PSM to estimate the impact of mental health interventions received by employees at the worksite after the World Trade Center attacks among workers in New York City. The authors used data from telephone interviewees with adults in a household survey conducted one and two years after 9/11 to match intervention cases to non-intervention control cases based on a bias-corrected nearest-neighbour algorithm. Their findings from matching with PSM suggest that about 7% of approximately 425 000 adults reported positive outcomes (such as reduced alcohol dependence, binge drinking, depression, severity of post-traumatic stress disorder and anxiety symptoms) resulting from receiving employer-sponsored, worksite crisis interventions related to the attacks.

In PSM, those members of the comparison group that do not match those in the intervention group are discarded. Once matching is completed, a balancing test is performed to ensure there is no statistically significant difference between the mean characteristics of the matched intervention and comparison groups. Finally, the impact is estimated by calculating the difference between the outcome indicator of interest for the intervention units and the average value for the matched comparison individuals, and then averaging over all these differences. Another interesting application of PSM is the study by Gomez and colleagues *(8)* which exploits data collected as part of a large-scale evaluation of an early childhood education intervention related to earthquakes in Santiago, Chile. The data included 4-year old children who had experienced, and who had did not experienced, the severe earthquake episodes of 2010. These children were then matched through PSM to find that the earthquake affected lower scores on some early language and pre-literacy assessments of children that had experienced the earthquake. A further example is provided as Case Study 4.5.1, which assessed the impact of humanitarian aid on food security in the Republic of Mali.

There are several statistical packages (such as Stata and R) that allow to implement PSM analysis through pre-built commands.

### Advantages and disadvantages of propensity score matching

The two main advantages of PSM are that it easily lends itself to establish the propensity score of being treated through a binary model, and that it can be done ex post, including in the absence of baseline data. If baseline data are not available, matching uses time invariant characteristics (such as sex and religion) and recall information on pre-intervention characteristics that can be reliably recollected. These features suggest the greater flexibility of the PSM model to accommodate many covariates.

#### Case study 4.5.1

#### Using PSM to measure the impact of humanitarian aid on the food security of rural populations in Mali *(9)*

PSM was used to measure the impact of humanitarian aid on the food security of rural populations in the Mopti region of Northern Mali.

The evaluation exploited data from a unique pre-crisis baseline in the region to use matched difference-in-difference methods to estimate whether access to different forms of food assistance improved household food expenditures, food and nutrient consumption, and the long-term nutritional status of children. The existence of baseline data enabled the matching of ‘intervention’ households with comparable ‘comparison’ households.

The measures used for matching were all pre-intervention (and so unaffected by it) and relate to both the selection into intervention and the outcome of interest (household expenditures, food consumption and a proxy for child nutritional status). The matching variables were both village-level measures (the presence of a secondary school within 5 km and the presence of a market within 5 km) and household-level measures (including whether children were involved in past projects, feelings of safety and age of the household head).

The impact evaluation found that food assistance increased household non-food and food expenditures and micronutrient availability.

A disadvantage of PSM is that it relies upon matching on observables. If selection (participation) into the intervention is affected by unobservables, PSM will yield biased impact estimates for ex-post single difference estimates. When panel data are available, PSM is biased if the unobservables are time varying or affect differences over time. However, time invariant observable factors can be removed by double differencing, so that PSM would again be unbiased.

### 4.5.5 Regression Discontinuity Design and Interrupted Time Series

Regression discontinuity designs (RDD) are used when there is a threshold rule for allocation to the intervention (such as administration of a drug if patient has a heartrate or temperature above a specific value, or the poverty line, or villages on either side of an administrative boundary). The assumption, which is tested as part of the procedure, is that units in proximity to either side of the boundary are sufficiently similar for those excluded from the intervention for these to be a valid comparison group. The difference in outcomes between those near either side of the boundary, as measured by the discontinuity in the regression line at that point, is attributable to the intervention, and so is the measure of the intervention's impact.

Interrupted time series (ITS) is a specific application of RDD in which the threshold is the point in time at which the intervention came into effect. This can be a particularly relevant method where intervention effectiveness is sudden, rather than gradual, such as the completion of a bridge or major power transmission connection, or the sudden availability of relief services.

**Description**
RDD can be used when there is a threshold rule that determines eligibility for the intervention, where the threshold is based on a continuous variable assessed for all potentially eligible units of assignment (such as individuals, households or communities). For example, households above or below the poverty line, children born before or after the cutoff date for school enrolment in a specific academic year, or students above a certain test score are awarded a scholarship. If the threshold is imperfectly applied, a variation on the approach, called 'fuzzy RDD', can be used.

The threshold variable must not be one which can be manipulated to become eligible for the intervention, as that might lead to selection bias. As an example, an impact evaluation of the Tropical Cyclone Winston social protection top up transfers was conducted by the World Bank in 2016 *(10)*. The goal of the intervention was to provide additional assistance in the form of top-up transfers to the most vulnerable, as a key component of its disaster response, and the intervention and control groups were constructed based on the Poverty Benefit Scheme (PBS) eligibility (poverty score) threshold. The treatment group was formed from PBS recipient households (20% below threshold) in affected areas in the Republic of Fiji that would also receive the intervention (top-up PBS benefit) after the cyclone. The control group was formed from the PBS-evaluated (before the cyclone) households in affected areas that were not eligible for PBS, as they were above (but within 20%) the threshold. The disaster responsive social protection intervention, in the form of top-up transfers to beneficiaries, was found to be an effective response following the cyclone.

In ITS, the threshold is the point in time at which the intervention or policy was introduced. In the case of a policy, this point in time is common to all households but other interventions (such as electrification or connection to a sewage disposal system) may affect different communities at different points in time. The threshold should be unique to the intervention. Clearly, those on either side of the threshold have some differences. In addition, the threshold criteria may be correlated with the outcome, so that there is selection bias if simple comparisons are made. For example, scholarships are awarded to improve learning outcomes, but those with better learning outcomes are given the scholarships. Older women are more likely to get breast cancer, and it is older women who are selected for screening for this cancer. However, those near either side of the threshold are also much more similar. Regression discontinuity is based on a comparison of the difference in average outcomes for these two groups.

Another interesting application of this method comes from the study of Mezuk and colleagues *(11)* who used the September 11 2001 attack as the discontinuity (cut-off) point to investigate its impact on the average monthly suicide rate in New York City. Using average monthly suicide rates data between 1990 and 2006, the study found no net change in suicides rates just before and immediately after the attacks, suggesting that factors other than exposure to that particular traumatic event may have been driving the risk of suicide in the population studied.

An iterative approach is used to determine the margin around the eligibility threshold. Initially, one sets a small margin and checks for balance of the resulting intervention and comparison group units. If the match is good, the margin may be widened a little and balance checked again. This can be repeated until the samples start to become dissimilar (that is, there is no longer balance between the two groups). When the sample is established, a regression line is fitted to the sample around the threshold. The sample for the regression is restricted to observations just on either side of the threshold. Specifically, the outcome indicator is regressed on the selection variable (such as test scores and an intercept dummy). The intercept dummy is a dichotomous variable, taking the value 0 for observations below the threshold and 1 at the threshold and above it.

### Advantages and disadvantages of RDD

RDD controls unobservables better than other quasi-experimental matching methods. It can also often use administrative data, thus reducing the need for data collection (see Chapters 2.4 and 4.4). The main limitation of RDD is that it is usually valid only for observations relatively close to the discontinuity point. Hence, a challenge for RDD is often to find a sufficiently large sample of observations on either side of the threshold. Further, the impact is being estimated only for the population close to the threshold. The estimate is what is called a local area treatment effect (LATE), rather than an average effect for the whole population in the intervention group. In principle, this limitation restricts the external validity of the approach.

Case Study 4.5.2 provides an example of how RDD was used to measure the impact of a winter cash assistance programme for Syrian refugees in Lebanon.

### Case Study 4.5.2
### Using RDD to measure the impact of a winter cash assistance programme to Syrian refugees in Lebanon *(12)*

The evaluation assessed the impact of cash on household well-being among Syrian refugees in Lebanon and whether cash might attract refugees to regions with assistance. The RDD design exploited the targeting approach of the cash assistance programme itself. Cash was given at high altitudes to target assistance for those living in the coldest areas during the winter months (households did not know beforehand that there would be an altitude eligibility cutoff). When the eligibility cutoff was set at 500 meters, households residing at 501 meters and above (intervention group) were included, while households residing at 499 meters or below (comparison group) were excluded. Intervention and comparison groups had very similar characteristics before the start of the programme, so differences measured after the programme's implementation represent the causal impact of cash assistance.

The impact evaluation found that the current value of cash assistance was inadequate because beneficiaries' income was so low that they were forced to use the cash assistance to satisfy other basic needs, in particular food. It also found that cash assistance increased access to school, reduced child labour and that the cash assistance programme had no pull factor on refugees settling in communities where cash was distributed.

## 4.5.6 Instrumental variables approach

The instrumental variable (IV) method is a regression-based estimation of the outcome variable of interest on either a project dummy or a measure of participation in the intervention group *(13)*.

In the conventional ordinary least squares (OLS) approach, the outcome is regressed on a dichotomous intervention dummy variable. The problem with this approach is that selection bias can affect the estimate of the impact coefficient. If selection is entirely based on observables, and the regression has included variables on all those observables, then OLS will indeed yield a valid impact estimate. However, if – as is more frequently the case – there are time varying unobservables, then cross sectional OLS models on differences will yield biased impact estimates. IV estimation is the technique used to remove the bias. It is an OLS regression in which the variable which is the source of the endogeneity problem is replaced by an instrument satisfying the following two conditions:

i. To be correlated with the probability of intervention (programme participation)
ii. To be uncorrelated with the outcome, except through its effect on the intervention.

When more than one instrumental variable is identified, the procedure is implemented as two-stage least squares: first one regresses the endogenous variable (the one measuring intervention participation) on the instruments and calculates its fitted value, then the outcome equation is estimated replacing the endogenous variable with the fitted values from the first stage. The estimated impact is the coefficient on the instrument. It is important to have determined the instruments before data collection starts, so that the relevant questions are included in the survey instruments.

### Advantages and disadvantages of IV

The advantage of IV is that if a valid instrument is found, both observable and unobservable sources of selection bias are controlled for. The main disadvantage of the method is that it may be difficult to find a valid and defendable instrument, because many factors that affect decisions to use an intervention typically also affect outcomes.

Case Study 4.5.3 provides an example of the use of IV to measure the political effects of environmental change.

### Case Study 4.5.3

### Using instrumental variables to measure the political effects of environmental change to understand the disaster–violence nexus *(14)*

In 2004, Sri Lanka was hit by a massive tsunami that killed more than 35 000 people and destroyed over 78 000 homes in that country alone. By May 2006, the Government of Sri Lanka had spent more than US$200 million on recovery, reconstructing at least 40 000 houses *(14)*. This study examined whether post-disaster reconstruction triggered further intrastate violence to explain civil unrest after the disaster.

The author addressed the endogeneity problem between reconstruction processes and violence (that is, that reconstruction is endogenous to violent events, but noted that there may be also a reverse causation if future violence limits current reconstruction efforts in disaster zones) by using the wave heights in the tsunami as an IV for post-war housing reconstruction.

The results suggest that an increase in housing construction is associated with the number of violent events, while the number of destroyed houses has no discernible impact on violence. Therefore, the paper plausibly concludes that reconstruction is a manipulable strategy that policy makers can use to respond to disasters through different post-disaster measures.

### 4.5.7 Conclusions

The chapter introduces some of the non-experimental quantitative methods that are available for impact evaluation studies in Health EDRM. These approaches are likely to be appropriate in establishing impact of interventions when random assignment is not be possible. Strengths and limitations of these approaches are illustrated with references to specific studies from disasters and other health emergencies. In general, best practice in planning a research study is to consider which approach is most appropriate and feasible at the design stage in order to prepare data collection tools and think of the best sampling strategy to get a good match. For example, PSM requires that data collection includes suitable matching variables and IV requires that data is available for one or more valid instruments. Oversampling will be necessary if observations will be discarded in establishing the regional of common support.

Moreover, where possible, it is best to use a combination of methods to ensure the most reliable and credible results on the impact of the intervention being assessed. For example, it is much better when possible to exploit baseline data for matching and using the difference-in-difference strategy. Similarly, if an assignment rule exists for the project, it would be ideal to match on this rule and subsequently do a regression discontinuity design.

### 4.5.8 Key messages

- **Impact estimates are possible in the absence of randomization, but still need data from a comparison group that did not receive the intervention.**
- **The available methods may be subject to selection bias.**
- **It is important to test for baseline balance to check if bias based on observables has been removed.**
- **The reliability of matching and the ability to calculate a double difference estimate are enhanced by the availability of baseline date for the intervention and comparison groups.**

### 4.5.9 Further reading

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# 4.6

# Health-related risk modelling

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## 4.6.1 Learning objectives

To have a basic understanding of some modelling methods that might be applied in research studies relevant to the following issues for health emergency and disaster risk management (Health EDRM):

1. Short-term environmental health associations.
2. Factors associated with the uptake of protection behaviours.
3. Trends of influenza.
4. Health-related vulnerability index.

## 4.6.2 Introduction

Health EDRM is an important approach for reducing the numerous public health impacts of disasters and emergencies (Chapter 1.2). Other chapters in this book describe research methods that require the collection of new data in prospective studies; this chapter complements these by discussing the use of statistical modelling to establish mathematical associations between variables. The chapter focuses on health-related risk models that are applicable to Health EDRM and discusses models for four particular topics: short-term environmental health associations; factors associated with the uptake of protection behaviours; trends in influenza; and health-related vulnerability index.

### 4.6.3 Models for evaluating short-term environmental health associations

Hydrometeorological hazards (that is, hazards related to water and weather-related events) are common triggers of disasters and account for about 95% of the people affected by disasters caused by natural hazards in the past 50 years *(1)*. Climate change is causing these extreme events to become more common and severe, leading to further impacts on human health. Improved weather forecasting and better understanding of the health risks of extreme environmental events is allowing for the implementation of effective health protection plans and improvements in resource allocation. These are supported by modelling methods for evaluating short-term associations between environmental exposures and health outcomes, and this section uses ambient temperature as an example to illustrate this. Extreme temperatures are a silent killer, due to people‘s lower awareness compared to other hazards *(2)*, and have caused substantial public health problems *(3-7)*.

Similar to other environmental exposures (air-pollutants, storms, for example), ambient temperature usually has a short-term association with health outcomes, ranging from hours *(8)* to weeks *(9)*, depending on the degree of exposure and the health outcome considered. A delayed effect is commonly reported for the temperature-health association, but it is not always linear. For instance, since both extreme high and low temperature may cause adverse effects on human health, there may be a v-shaped association between ambient temperature and the risk of adverse health outcomes. Combined with a seasonal effect and some other confounding effects (such as air-pollutants and population-level demographic factors), the estimation of a temperature-health association is complicated. A time series design is the most common method to reveal these short-term temperature-health associations *(10)*.

Time series data are a series of sequential records in equal time units, such as the number of deaths and the average daily or weekly temperature within a specific time period. Bhaskaran and colleagues discussed and compared time series designs used in environmental epidemiology, identifying three main types of time series study: time stratified model, periodic functions and flexible spline functions *(11)*.

For the time stratified model, exposure and outcome are associated in stratified time units. Time intervals are indicated by indicator variables (such as time period: 1, 2, up to “n”) instead of the true date record. This type of model is relatively easy to understand but many parameters are included in the model and it cannot facilitate the calculation of the continuous effect from one time unit to another *(11)*.

Periodic functions (Fourier terms) model exposure and outcome by using periodic functions such as sine and cosine function to represent the periodic characteristics (such as calendar months). This model type creates smooth predictions but the period of the pattern is fixed, and this might not be appropriate for representing trends that are mathematically complicated and do not have a fixed pattern *(11)*.

Flexible spline function is a modelling approach combining different polynomial curves *(11–12)*. This design is most commonly applied in assessing short-term associations between temperature and health outcomes *(13–14)*. It allows the health outcome to be linked to a number of exposures with different non-linear associations at the same time. This is an important feature, because most temperature-outcome associations and long-term trends are non-linear and non-periodical. Another reason for using a flexible spline to model long-term trends is that it helps control the long-term demographic factors at a population level. For example, smoking is a potential confounder of the risk of admissions to hospitals for breathing problems when studying the association with temperature but, because the proportion of people in a population who smoke does not change significantly from day to day, it does not affect the daily association between temperature and these admissions. Therefore, overall changes in the proportion of smokers can be captured by fitting a spline function for the long-term trend.

To incorporate the non-linear delayed effects of ambient temperature on health outcomes into the spline model, Armstrong *(15)* and Gasparrini *(16)* introduced the Distributed Lagged Non-linear Model (DLNM) and the corresponding R package dlnm, respectively. This modelling approach is a three-dimensional data analysis. It considers the exposure, health outcome and the delay (time) dimension at the same time. In DLNM, spline functions can also be applied on the time dimensions, thereby addressing the need to model the non-linear delayed effect in exposure-outcome associations. The combination of flexible spline approach and DLNM tackles most of the concerns when evaluating short-term environmental health associations but is complicated because it involves one more dimension than other traditional time series designs. Similar to other time series approaches, the problem of effect modification by other factors (such as age and gender) still exists and needs to be handled separately (for example, by conducting subgroup analysis). More details about the method and some examples are available elsewhere *(17)*.

### 4.6.4 Identifying factors associated with the uptake of protective behaviours during extreme events

Applying appropriate protective behaviours during extreme events can lower exposure to hazards and hence reduce health risk. Sociodemographic factors *(19)* and knowledge, attitude and practice (KAP) *(20-21)* are common examples of determinants of health behaviours. Identifying associated sociodemographic factors and understanding KAP for a protective behaviour provides evidence to support health promotion policies. This section introduces a statistical method for identifying factors associated with the uptake of protective behaviours, using data collected from a cross-sectional KAP survey.

Logistic regression is a regression model characterized by one binary dependent variable (outcome) and multiple independent variables (explanatory variables) *(22)*. It allows users to investigate the association between the outcome variable and an explanatory variable with adjustment for other confounders. It is used widely for identifying factors (such as knowledge and gender) that might be associated with the likelihood of a group of people acting in a certain way (taking or not taking action, for example) and comparing this to a reference group of other people.

In Health EDRM, there are usually several explanatory variables to consider but including too many explanatory variables in the model compromises its power to reveal the real associations. A general guide is that there should be at least ten cases for each explanatory variable in each outcome group *(22)* and the power increases with increasing numbers of cases. To reduce the number of explanatory variables in a regression model, univariate analysis, such as the chi-square test (for categorical variables) and t-test (for continuous variables), can be used to provide a quick assessment of the potential associating factors. Explanatory variables showing potential association with the outcome in the univariate analysis, together with some core explanatory variables (supported by literature or hypothesis) are then entered into the logistic regression model. Model selection (the process of selecting explanatory variables for a model) can also be done by removing non-significant variables from a full model or adding variables and keeping those that are significant (see Case Study 4.6.1).

**Case Study 4.6.1**
**Data collection by telephone survey**

For a community with a high level of landline telephone penetration, data collection through a telephone survey might be an appropriate way to examine knowledge, attitude and practice (KAP) in community behaviour patterns. A population-based telephone survey among the Hong Kong population investigated their weather information acquisition pattern during an intense cold spell *(23)*. The Chi-square test and a logistic regression model were used to identify independent associated factors in a two-stage analysis. Univariate analyses were used to identify potential associated factors with the outcome and factors with a p-value from the chi-square test of less than 0.20 were entered to the second stage of the analysis, the multiple logistic regression analysis, to assess their independent association with the outcome. In the univariate analyses, educational attainment, age and marital status were significantly associated with current use of smartphone apps to acquire weather information. In multiple logistic regressions, only older age and lower education level remained significantly associated with lower smartphone app usage.

### 4.6.5 Prediction and forecasting of influenza trend

Influenza is a global public health burden, usually associated with cold-like symptoms but leading to serious illnesses in vulnerable groups (for example, young children and the elderly) *(24)*. Influenza causes health and economic burdens, with loss of work or school hours for patients and caretakers, large numbers of emergency room visits, hospitalizations and deaths *(25–27)*. Influenza viruses gradually mutate and when a new contagious strain emerges in a community without immunity, this may lead to an epidemic. To reduce the risk of disease outbreak and disease burden, accurate prediction of strain types and the number of cases is important for primary prevention strategies. Accurate prediction facilitates effective vaccine strain selection and resource planning for the healthcare sector, and various prediction models have been developed to meet different purposes and region-specific environmental conditions. This section introduces predictive models for vaccine selection and the forecast of influenza activity *(28–30)*.

Vaccine selection is conducted annually, in general, and is a year-long process because of the long production time for the vaccines (approximately 6 to 8 months). The process is managed collaboratively between WHO and professionals around the world, supported by global surveillance data related to influenza virus circulating in humans *(29)*. Employing present and past data, predictive models are used to identify and predict emerging influenza clades (that is, groups of virus strains that are believed to comprise of evolutionary descendants of a common virus ancestor) that may be dominant in the following year. Most of the predictive models focus on the biological determinants of the evolution of influenza, with scale from molecular, within-host, population, regional to global level. Some models infer phenotypic properties of the current population *(29)*.

Antigenicity-stability fitness model *(31)*, Epitope Clade Growth *(32)* and Local Tree Shape *(33)* are probabilistic evolutionary focused models for predicting future viral populations *(29)*. Antigenicity-stability fitness model is a validated model estimating expected growth rate (fitness) of viral clades by input of a few years of genetic and antigenic data and is able to predict frequency of trajectory of clades for about one year ahead *(31)*. Epitope Clade Growth, a model based on genealogical tree, estimates antigenic differences by extrapolating recent growth hemagglutinin clades seeded by epitope mutation *(32)*. Local Tree Shape is another genealogical tree-based model. It estimates recent clade growth from information stored in the local shape of a hemagglutinin genealogical tree *(33)*.

Linking antigenic properties and genetic data, and identification of proposed vaccine strains are two ways of inferring phenotypic properties *(29)*. They estimate the effectiveness of current vaccines for the emerging influenza strains and identify new antigenic variants at an early stage of expansion *(29)*. Strain selection involves complex decisions that require the integration of the results from different models at different scales. Integration and interpretation of data for decisions are key challenges *(29)*.

Forecasts of influenza activity have been conducted worldwide to support preparedness activities *(28, 30)*. These forecasts can be based on single or multiple measures. Typical measures are peak periods (time), peak and outbreak magnitude and case counts by day or week *(30)*.

There are two main modelling approaches: (i) statistical models without consideration of the epidemiology process and (ii) epidemiological models *(28)*. The common statistical models are time series models, generalized linear models, Bayesian network and classification methods *(28)*. The susceptible-infections-removed (SIR) models and agent-based models (AMBs), which include exposure, infection, transmission and behaviours in the calculations, are the common epidemiological approaches for forecasting influenza activity *(28)*. Agent-based models can be operated by simulation algorithm to estimate key epidemiological parameters and then to forecast future activity (see Case Study 4.6.2). While time series models can capture the temporal dependence of health outcomes, epidemiological approaches are able to account for health-related human behaviours and address questions related to the impact of prevention measures on health. Dynamic virological data and syndromic influenza-like illness are common input data for surveillance data forecast models *(28)*. Real-time forecast models, making use of retrospective forecast information have been developed for temperate regions, with seasonal winter epidemics such as the USA *(34–35)*. However, these real time models performed less well in subtropical regions, such as Hong Kong SAR, with a two peak or year-round pattern *(36)*.

**Case Study 4.6.2**
**Forecast Model - Simulation Optimization (SIMOP)**

Nsoesie and colleagues *(37)* introduced a **sim**ulation **op**timization (SIMOP) approach for forecasting influenza epidemic infection curves. This combines the individual-based epidemiology model and the optimization technique for model parameters estimation (Nelder-Mead simplex method). The three model parameters estimated were the disease transmissibility, incubation and infectious period distribution. The individual-based model consisted of a dynamic social contact network (representing Montgomery County in Virginia, Miami, Seattle and surrounding metropolitan regions of the USA) and a disease model with the several assumptions.

There were three main steps for the SIMOP: (i) initialize the individual-based model and the Nelder-Mead simplex method, (ii) run the Nelder-Mead algorithm to find new parameter sets, and (iii) simulate an epidemic using the proposed parameter set and evaluate the objective function. Steps 2 and 3 were repeated for convergency. The input measures were the sequential daily or weekly number of cases during the period of epidemic, which were simulated by the estimated disease transmissibility, incubation and infectious period distribution. The model was used to forecast the epidemic peak timing, counts of infected individuals and cumulative infected individuals.

The model predicted the peak time at seven weeks before the actual peak. Forecasting the peak count of infected and cumulative infected individual was more challenging because of the possibilities of the epidemic curve trajectories, but the forecast was found to be accurate for Montgomery County.

## 4.6.6 Compositing indicators/index to measure vulnerability

Climate change is set to increase the frequency and intensity of disasters due to natural hazards *(38)*. Risk assessment tools are important for saving lives and reducing losses in disasters. During disasters, the number of deaths, the number of people affected and economic loss are not only determined by the hazard itself, but also by the proportion of population exposed and the vulnerability of the community (Chapter 1.3). Understanding risk in all its dimensions is essential for effective Health EDRM, and as such, the collection of large volumes of data is a major focus of research and public interest, because it presents opportunities to describe reality accurately (Chapter 2.4). However, although large amounts of data provide information from many perspectives,there may be too many variables for a clear understanding. This problem is sometimes known as the “curse of dimensionality”.

If there are a large number of variables in a dataset, a dimension reduction method can be applied. This maps the numerous original variables into fewer independent dimensions, based on their correlation to each other. It is therefore more meaningful to summarize data as a few independent dimensions, while preserving as much of the original information as possible *(39)*.

On some occasions it is easier to interpret one composite index resulting from dimension reduction, rather than indicators from multiple perspectives, despite the simplification of the original data. A composite index can allow multi-country comparisons for complex issues, such as society development, vulnerability to environmental hazards and urban heat islands. A good quality composite index is based on careful variable selection and appropriate use of the dimension reduction method, and can facilitate communication and policy making.

Principal components analysis (PCA) and factor analysis (FA) are two examples of linear dimension reduction methods. They attempt to explain a multivariate dataset by reducing them into a smaller number of dimensions. PCA is one of the oldest multivariate techniques and is useful for displaying multivariate data as a set of dimensions (called ‘principal components’). It simplifies the complexity by transforming correlated variables into a set of uncorrelated principal components *(40)*. Each principal component is rated according to the extent to which it represents the original dataset, and most of the information from the original variables is captured by the principal components rated the highest (see Case Study 4.6.3). In summary, PCA provides a concise summary of the original variables, with no probabilistic or statistical assumptions.

### Case Study 4.6.3
### Principal components analysis (PCA) to develop a Heat Vulnerability Index

PCA was used to combine socioeconomic indicators into a Heat Vulnerability Index in London, United Kingdom *(41)*. Nine variables were identified: households in rented tenure, households in a flat, population density (persons/hectare), households without central heating, population above 65 years old, population with self-reported health status, receiving any kind of social benefit, single pensioner households and ethnic group. These were included in the principal components analysis. Four principal components were then identified, which could be interpreted as high-density housing, poor health and welfare dependency, being elderly and isolated, and poor housing quality. Principal component loadings are weighted according to the variance they explain and summed to form the Heat Vulnerability Index. In this way, the number of independent factors (dimensions) associated with the outcomes could be decreased and interpretation of the findings was simplified.

If statistical assumptions are added into principal components analysis, the principal components analysis becomes a factor analysis (*42)*. The results from principal components analysis and factor analysis would not differ dramatically if the specific variances added are small. Like principal components analysis, factor analysis is a classical technique used to derive fewer dimensions from a large set of variables. However, unlike principal components analysis, factor analysis can allow for further statistical inference and support assertions about a population (see Case Study 4.6.4). Although the use of factor analysis draws considerable criticism (due to the lack of uniqueness of the factor loadings, for example), it is a useful approximation for the truth and a suitable starting point for further investigation.

**Case Study 4.6.4**
**Factor analysis to develop a Health Vulnerability Index**

By using FA to create a linear combination of indicators, a Health Vulnerability Index for disaster risk reduction along the Belt and Road Initiative was developed *(17)*. The index is based on three latent factors: population status, disease prevention and coping capacity. These were derived from nine indicators: proportion of the population below 15 and above 65 years, under-five mortality ratio, maternal mortality ratio, tuberculosis prevalence, age-standardized raised blood pressure, physician ratio, hospital bed ratio, and coverage of the measles-containing-vaccine first-dose (MCV1) and diphtheria tetanus toxoid and pertussis (DTP3) vaccines.

Non-linear dimension reduction methods are an extension of the linear methods and are useful if Euclidean distances (that is, straight-line distance between two points) fail to capture the dissimilarity between the observations. These methods reduce the volume of data by simplifying it into a set of low-dimensional coordinates that preserve distances in the high-dimensional space as much as possible, but involves non-linear transformations of the data.

### 4.6.7 Conclusions

Risk modelling is well established and can be used in helping resource allocation in Health EDRM. In recent years, it has been applied to a wide range of temperature-related studies, but consistent associations were not often found for other climate-related topics such as rainfall or sea level rise *(17)*. Risk modelling in other contexts (such as complex emergencies) or between varying contexts (such as rural versus urban) is also needed to understand health-related impact of hazards and disasters.

## 4.6.8 Key messages

- **Time series analysis is widely used for establishing short-term associations between exposures and health outcomes.**
- **Factors associated with protective or preparedness behaviours can be identified by applying the multiple logistic regression method.**
- **Linking Antigenic Properties and Genetic Data, and Identification of Proposed Vaccine Strains are two ways of inference of phenotypic properties for influenza vaccine selection. They estimate the effectiveness of current vaccine strains for the emerging strains and identify new antigenic variants at an early stage of expansion.**
- **In predicting influenza trends, epidemiological approaches, such as the susceptible-infections-removed models and agent-based models, consider human behaviours and address questions related to the impact of prevention measures.**
- **In constructing a health-related risk index, dimension reduction approaches such as principle component analysis (PCA) and factor analysis are widely used to simplify the display of multivariate data.**

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## 4.7

# Evaluating economic impacts in health emergency and disaster risk management

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## 4.7.1 Learning objectives

The learning objectives of this chapter are to:

1. Understand how economic evaluations and economic impact studies can support decision making in health emergency and disaster risk management (Health EDRM).
2. Know the methods available to researchers conducting these studies.
3. Be aware of research limitations, including evidence gaps and methodological challenges.

## 4.7.2 Introduction

Economic evaluations and economic impact studies are important because they can help decision makers manage competing spending priorities and maximize the value of their financial budgets. Economic impact studies quantify the costs and consequences of past or potential events. Economic evaluations are a structured way to evaluate costs and consequences of a programme or policy compared to an alternative course of action. Conducting these studies and applying their findings can be part of prevention, preparedness, response and recovery activities in Health EDRM.

This chapter provides an introduction to economic evaluations. It outlines the value of evaluating economic impacts, key concepts involved in conducting economic evaluations, and current limitations in the context of Health EDRM. In this chapter, the term “researchers” refers to individuals and groups undertaking economic studies.

## 4.7.3 Why conduct economic evaluations and economic impact studies?

Economic studies describe and explain the implications of a specific event or health issue, and potential risk management actions, in terms of financial and non-financial resources. This information can help justify the size of overall spending and support specific resource allocation decisions about which policies and programmes to use to improve health outcomes *(1)*.

## 4.7.4 Informing decision making

Economic studies that can help inform Health EDRM include economic evaluations and economic impact studies. Economic evaluations explicitly compare the costs (use of resources) and consequences (effects) of a programme or policy with an alternative course of action *(2)*. This alternative may incorporate another programme or policy, or simply reflect the current situation. Economic impact studies evaluate actual or potential economic outcomes related to a specific intervention, event or health-related issue, such as those associated with a heatwave or an infectious disease outbreak. Findings from both economic evaluations and economic impact studies can be inputs for decision-making tools that account for broader economic and non-economic evidence, such as multi-criteria decision analysis (MCDA). In such cases, MCDA combines findings from economic studies with additional decision-making factors, such as budget constraints or implications for equity and fairness *(3)*.

Various stakeholders can use the information created by economic studies to evaluate past events, manage current challenges or plan for future risks. These stakeholders include government agencies, private companies and civil society groups. For example, findings from economic studies can inform the costing tools used to plan and implement measures to prevent, prepare, respond to and recover from health emergencies and disasters *(4)*. Economic studies also help to describe inequality and hardship, which might link to socioeconomic and demographic characteristics such as income status, gender and age. Section 4.7.5 “Understanding the economic impact of health emergencies and disasters” discusses these topics further.

Economic evaluations help support population-level decisions about which health services, medicines and other medical technologies should be funded and made available. Economic studies can help offer a reference point for balancing and aligning different stakeholders’ priorities, such as those of patients and the public, taxpayers and politicians, insurance providers, healthcare providers, and health technology producers *(5)*. The term “health technology” refers to the application of organized knowledge and skills in the form of devices, medicines, vaccines, procedures and systems developed to solve a health problem and improve quality of lives *(6)*.

### 4.7.5 Understanding the economic impact of health emergencies and disasters

Health emergencies and disasters lead to economic impacts on households, health systems and the economies as a whole (macroeconomic impacts). Economic studies help describe these impacts.

Illness or injury can create healthcare costs and income losses that put stress on families and households. Healthcare costs create direct economic impacts through spending on health services or medicines, which limit funds available for other household expenditures or create the need for raising additional funds, potentially via incurring financial debt. An inability to work, due to illness or caring for others who are sick, can create indirect economic impacts (see 4.7.7) through income losses and associated financial distress.

Proactive policies to guarantee healthcare access and support wellbeing can help reduce household and community impacts and hardship, which may be distributed inequitably between different socioeconomic and demographic groups *(7–8)*. For example, after Super Typhoon Yolanda devastated parts of the Philippines in 2013, the response included rapidly adapting existing healthcare funding systems. The national insurance agency (PhilHealth) guaranteed hospital services to all affected persons seeking access, regardless of whether insurance policies already covered the person's healthcare costs *(9)*. This meant that people who did not have the necessary health insurance could still access healthcare, without concern about further typhoon-related hardship due to additional costs.

Damage and disruption can restrict healthcare services and, at the same time, create increased demand due to direct and indirect health impacts (see 4.7.7). Damage to infrastructure, constrained workforce capacities and disruption to physical supply-chains can limit the availability and accessibility of health care *(10)*. This can mean that illness and injury are not treated, leading to worse health outcomes and higher long-term health-related costs *(11–12)*. Economic studies can support proactive risk management policies, ensuring that healthcare services can adapt to restrictions and meet sudden increases in healthcare requirements *(13)*.

Disasters and emergencies also create macroeconomic impacts, by disrupting the functioning of government institutions, private organizations and the overall economy. Government institutions are stressed by responses to challenging public priorities, while private organizations lose potential revenues from the goods and services they produce, and the supplies of labour and other inputs needed to produce them. This disruption will negatively impact both economic output and people's general welfare *(14)*. Examples of research into the macroeconomic impacts of climate change, natural hazards, and infectious disease outbreaks have found that climate change-related increases in exposure to extreme heat in South-East Asian countries may restrict feasible annual working hours by 15% to 20% by 2030 *(15)*, that disasters due to natural hazards lead to impacts to wellbeing and losses to economic consumption that result in over US$520 billion in economic losses per year *(16)*, and a severe pandemic outbreak of infectious disease could reduce global economic output by US$500 billion if there were 720 000 associated deaths in a single year (forecast conducted in 2017) *(17)*.

Table 4.7.1 provides examples of the sorts of economic impact studies that can inform decision makers and help address economic impacts on households, health systems, and the economy as a whole. These studies were obtained from two evidence reviews of economic studies and are a sample of the (limited) available economic evidence in health emergency and disaster risk management published prior to 2020 *(18-19)*. Two studies focused on infectious disease outbreaks (Ebola Virus Disease) and four focused on extreme weather events (hurricanes and heatwaves). Some of these studies offer a range of estimates, which reflects their accounting of potential uncertainty in their findings (see 4.7.10 Ten steps to conducting an economic evaluation).

### Table 4.7.1 Examples of economic impact studies

**Infectious disease outbreaks: Ebola Virus Disease (EVD) in West Africa (2014-2016)**

Bartsch and colleagues *(20)* estimated costs associated with individual patient cases of EVD.

- The authors looked at individuals who survived and who died after receiving care for EVD, in Guinea, Liberia and Sierra Leone during the 2014-2016 outbreak. Estimates of costs included supportive care, personal protective equipment, wages for health workers, and productivity losses linked to health-related absence from work.
- They compiled costs associated with 17 908 cases of EVD and 6373 deaths caused by EVD, as of December 2014, to estimate total societal costs of between US$82 million and US$356 million.

Kirigia and colleagues *(21)* estimated economic losses associated with EVD deaths.

- The authors focused on individuals who died in Guinea, Liberia, Mali, Federal Republic of Nigeria and Sierra Leone during the 2014-2016 outbreak. They measured losses based on expected overall losses of economic outputs, excluding those related to the provision of health care.
- They compiled costs associated with 11 234 deaths from 27 543 EVD cases, as of 28 June 2015, and estimated that cumulative future economic losses would be over US$155 million.

### Extreme weather events: Hurricanes in the USA

Fonseca and colleagues *(11)* forecast economic impacts associated with hurricane-related disruption to health care.

- The authors focused on individuals with diabetes impact by Hurricane Katrina, which made landfall in the USA in August 2005. Estimates of health outcomes included measures of blood sugar, blood pressure and lipids. They drew on a previous study to combine these measures to estimate life expectancy, quality-adjusted life expectancy, and future costs of diabetes-related complications *(22)*.
- They forecast that disruption to diabetes patients' access to healthcare services and supplies because of the damage to the health system might lead to US$504 million in additional healthcare costs over the lifetimes of affected individuals.

Zahran and colleagues *(23)* assessed mental health resilience and related economic impacts for individuals exposed to hurricanes.

- The authors focused on population impacts, specifically for single mothers, of two hurricanes which made landfall in the USA in 2005: Hurricane Katrina and Hurricane Rita.
- They measured costs by calculating expected declines in productivity and wages following the hurricane events. The authors found that, following the hurricane events, single mothers had over three times more poor mental health days and five times more days absent from work than the general population. These effects were linked to economic losses of US$4200 per person and a total of US$130 million for all single mothers in the affected population.

### Extreme weather events: Heatwaves in Australia and the USA

Toloo and colleagues *(24)* forecast healthcare costs associated with more common and more intense heatwaves.

- The authors focused on emergency department use by individuals impacted by heatwaves in Brisbane, Australia. They estimated emergency department use for a younger and older age group and linked use to health issues such as exacerbated cardiovascular issues, diabetes, and renal complaints. They estimated costs by combining data from 2012 and 2013, which described the costs of excess emergency department visits with forecasts for extreme temperature prevalence in 2030 and 2060.
- They forecast that expected heatwaves could increase emergency healthcare costs in Brisbane by between AU$78 000 and AU$260 000 in 2030 and between AU$215 000 and AU$1 985 000 in 2060, without adjusting for inflation.

Lin and colleagues *(25)* forecast healthcare costs associated with hospital admissions linked to a range of different heatwave scenarios.

- The authors focused on respiratory-related hospital admissions in New York, USA. They combined estimates of daily hospitalization costs with excess days of hospitalization per year attributable to extreme heat, using a range of scenarios forecast by the Intergovernmental Panel on Climate Change (IPCC).
- They estimated that heatwave-related annual admissions created additional costs of US$0.64 million per year from 1991-2004, with estimated excess costs of between US$5.5 and US$7.5 million per year from 2045-2065, and between US$26 and US$76 million per year from 2080-2099.

## 4.7.6 Key concepts involved in conducting economic evaluations

This section introduces the key concepts and steps involved in conducting an economic evaluation and offers some guidance on how to conduct an economic evaluation in the context of Health EDRM. Although the focus is on economic evaluations, some of the concepts discussed under the headings of 'Population' and 'Economic Outcomes' are relevant to researchers conducting economic impact studies. This information is a complement to, rather than a substitute for, established guidance on conducting and reporting economic evaluations *(26–27)*.

The following sections outline three elements involved in economic evaluations comparing the value for money of alternative programmes or policies: the target population, the economic outcomes, and the comparison methods. Other important elements include the interventions, comparison groups, and the time horizon for evaluating outcomes; as discussed in other chapters in this book. Specific concerns for researchers conducting economic evaluations are highlighted in the "Research limitations" section of this chapter (4.7.11).

## 4.7.7 Population

An economic evaluation focuses on the outcomes of a specific group of individuals, namely the study's target population. Researchers can define this population by its size and using factors such as the socioeconomic or demographic characteristics (such as income status or age) of the people within it, the interventions they receive and geographic area covered by the population. Researchers should also consider whether they define this population based on whether a health emergency or disaster directly or indirectly affected the people in the population. The meanings of "directly affected" and "indirectly affected" are outlined below.

**Directly affected**
People who have suffered injury, illness or other health effects; who were evacuated, displaced or relocated or have suffered direct damage to their livelihoods, economic, physical, social, cultural and environmental assets *(28)*. Examples of direct health effects include immediate illness due to an infectious disease or injuries such as wounding, blunt force trauma, and burns *(10)*.

**Indirectly affected**
People who, over time, have suffered consequences other than or in addition to direct effects. These may be due to disruption or changes in economy, critical infrastructure, basic services, commerce or work, and include social, health and psychological consequences *(28)*. Examples of indirect health effects include post-emergency sanitation issues leading to infectious disease outbreaks and disrupted access to healthcare services leading to untreated health issues *(10)*.

## 4.7.8 Perspective

Researchers use a variety of measures to estimate costs and consequences. One way to group these measures is to take a “payer perspective”, which focuses on healthcare use. Another way is to use a “societal perspective”, which accounts for a broader set of economic impacts *(2)*. The choice as to which economic outcomes should be included in a study is influenced by the amount of time and effort required to conduct the study, due to analysis requirements and the intended audience for the results of the study. For example, a payer perspective may meet the needs of a health insurance company focused on managing healthcare costs, whereas a government agency may prefer to take a societal perspective to account for broader impacts on health, wellbeing, and economic welfare. The choice of perspective for a study is often discussed in terms of the range of costs considered, but can also account for consequences considered.

**Payer Perspective**
Payer perspective focuses on costs and consequences linked to the use of (and payment for) healthcare. Payers can include a variety of actors directly involved in the provision and receipt of healthcare services. The main payers are usually government agencies or health insurers, depending on how healthcare is organized and financed in the country concerned. However, in many settings, patients and family members will incur costs associated with accessing or receiving health care. Medical costs and consequences may involve payments for access to care, medical supply costs, salaries for health workers and expected future healthcare costs related to changes in health outcomes. Non-medical costs and consequences may involve spending on transport, accommodation, and food by individuals receiving care and informal nursing care provided by their families.

**Societal perspective**
Societal perspective focuses on the costs and consequences, including but not limited to those measured in a payer perspective, which can be linked to health outcomes and healthcare use. Societal costs and consequences include broader societal concerns – such as employment, labour productivity, and consumption of goods and services other than health care.

Economic costs and consequences are measured based on the value of market or non-market resources. Market resources are purchased with money and have a defined price. They include wages for health workers and the cost of drugs. Non-market resources are not purchased with money and do not have a defined price. These include household work, volunteer services, and donated medical supplies. One way that researchers can estimate the economic outcomes associated with non-market resources is by using a proxy measure. A proxy is a variable that is more readily measurable and can act as a substitute estimate of costs and consequences, such as values of similar goods and services.

**Figure 4.7.1 Components of an economic evaluation of a healthcare programme (adapted from *(2)*)**

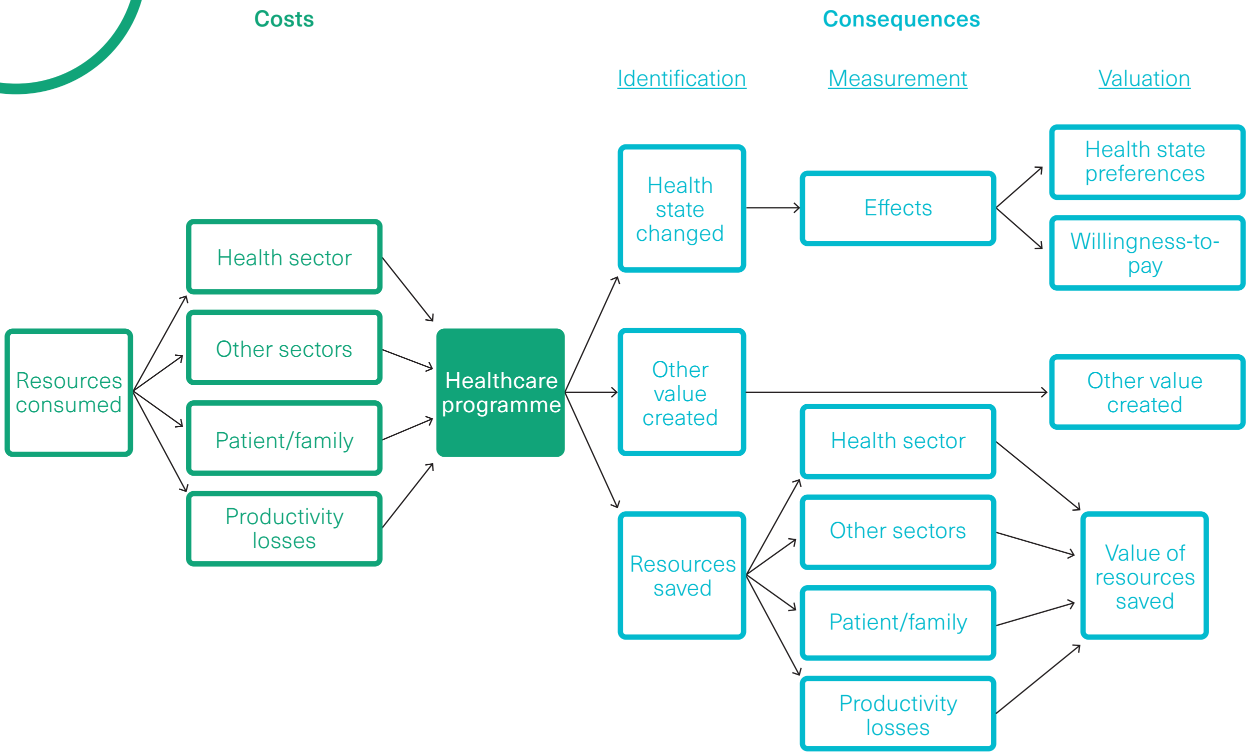

Figure 4.7.1 displays key pathways involved when estimating the costs and consequences involved in an economic evaluation of a healthcare programme. Costs reflect resource use across different sectors to deliver the programme, consequences reflect outcomes related to the programme's impacts on health and wellbeing. For example, costs for a vaccination programme might involve vaccine manufacture, delivery of vaccines to a health facility, and health workers providing vaccination services. Consequences for this programme might include immunization preventing future healthcare costs and losses to labour productivity. Researchers can adapt these pathways and the interaction between different nodes to vary their study perspective and focus on prevention, preparedness, response or recovery activities in Health EDRM.

## 4.7.9 Comparison Methods

There are several established methods for combining data on costs and consequences to evaluate economic outcomes *(2)*. The following paragraphs outline some of them. Other approaches to evaluating economic outcomes, not discussed in detail here, include extended cost-effectiveness analysis and the use of social welfare functions *(1)*.

**Cost-benefit analysis**
Cost-benefit analysis combines costs, positive consequences, and negative consequences to calculate a cost-benefit ratio or measure of net-benefit (benefits minus costs). Both costs and benefits are measured in monetary terms. This approach provides a clear estimate of relative economic outcomes, but only if it is possible to estimate the monetary value of costs and consequences.

### Cost-consequence analysis

Cost-consequence analysis compares costs and outcomes by placing them in discrete categories. Estimates are not combined to create a single measure or ratio. This approach allows the user of the research to make their own interpretation about the relative importance of different costs and consequences.

### Cost-effectiveness analysis

Cost-effectiveness analysis compares costs measured in monetary terms with outcomes measured via natural units. Examples of natural units for health-related outcomes include clinical endpoints (see Chapter 2.2), such as end of viral infection or alleviation of symptoms of depression, or life-years gained (which is the additional number of years of life that a person lives as a result of receiving a treatment). Case Study 4.7.1 summarizes a study that used cost-effectiveness analysis to compare antiviral stockpiling approaches for pandemic influenza preparedness.

### Cost-minimization analysis

Cost-minimization analysis compares interventions based on costs measured in monetary terms. This approach does not measure consequences and is only appropriate if the compared interventions have the same effect.

### Cost-utility analysis

Cost-utility analysis compares costs measured in monetary terms with consequences measured via a measure of health gain or ‘utility’. Examples of utility measures include:

- **Quality-Adjusted Life-Years (QALYs)** are a measure of additional life expectancy combined with the health-related quality of life. QALY measures are determined by surveying people’s evaluations of being in different health states, accounting for factors such as pain or mobility, through surveys and instruments such as the EQ-5D *(2)*.
- **Disability-Adjusted Life-Years (DALYs)** are a measure of life expectancy combined with years of healthy life lost due to mortality and/or morbidity associated with a health issue. DALY measures reflect the difference between a given health state and a benchmark that is based on the experience of a healthy life that reaches full life expectancy.

### Return on investment analysis

Return on investment analysis calculates the size of the difference between positive consequences and costs. Return on investment involves calculating net consequences (positive consequences minus negative consequences) and then expressing this figure as a proportion of costs. Typically, these studies consider only those costs and consequences that can easily be expressed in monetary terms. Case Study 4.7.2 describes a return on investment calculation for vaccine interventions, focusing on the resource costs and savings of a potential flu outbreak in Chicago, USA.

### Case Study 4.7.1
### Comparing the value of stockpiling approaches

Carrasco and colleagues *(29)* conducted an economic evaluation to assess arrangements for stockpiling antiviral medicines in anticipation of an influenza pandemic across ten high- and middle-income countries. They examined different stockpile sizes and impacts on eligible recipients of antivirals for prophylaxis and treatment. They focused on estimates of mortality associated with infectious disease outbreaks and the costs of antiviral stockpiles. Health risks were estimated by forecasting morbidity and mortality associated with pandemic risks over a 30-year time horizon, accounting for factors including seasonality and development of an effective vaccine. Economic outcomes included treatment costs and work absenteeism.

The authors estimated that stockpiles in higher income countries had a greater potential avoidance of expected costs, while stockpiles in lower income countries had more potential avoidance of mortality. Their findings showed that the USA could potentially avert potential future costs by US$22 billion, and that improved stockpiling in Indonesia could reduce expected mortality by more than 9 million deaths.

### Case Study 4.7.2
### Preparing for public health emergencies

Dorratoltaj and colleagues *(30)* conducted an economic evaluation to understand vaccination priorities and economic outcomes during disease outbreaks. They examined vaccine use versus a base case scenario of no vaccine intervention during moderate, strong, and catastrophic influenza outbreaks. They focused on people living in Chicago, USA and examined impacts across different population sub-groups based on age and levels of health risk. They estimated economic outcomes by linking expected health impacts associated with an influenza-like illness with healthcare costs and productivity costs taken from another study *(31)*.

The authors included cost-benefit and return on investment methods in their analysis. High-risk people under 19 years of age had the highest return on investment in a catastrophic influenza pandemic scenario, with US$249.16 saved for each US$1 invested in vaccinations. The lowest return on investment in a catastrophic influenza pandemic scenario was among non-high risk people aged between 20 and 64 years, with US$5.64 saved for each US$1 invested in vaccinations. Net benefits were highest among high-risk people aged between 20 and 64 years in all pandemic scenarios.

Having identified and implemented a comparison method, researchers can account for uncertainty their economic study results by conducting sensitivity analyses. A sensitivity analysis measures variations in results based on changes to the inputs informing the costs and consequences in an economic evaluation. Changes can involve varying the value of an input (such as implementation cost or population characteristics) or other features of the study, such as the time horizon (number of months or years over which costs and consequences are estimated).

Variance in results displayed by sensitivity analyses, can help decision makers to understand how the variance in their input values affects the results of their economic evaluation and help researchers to reduce uncertainty in their inputs data (such as intervention effectiveness or costs). Researchers may also compare findings from different statistical models to help understand how different approaches to estimating costs and consequences will impact their results.

### 4.7.10 Ten steps to conducting an economic evaluation

The process of conducting an economic evaluation can be set out as a series of ten steps. These steps, adapted from questions created to help guide assessments of economic evaluations, are outlined below *(2)*.

These steps complement guidance elsewhere in this book on study design, such as in Chapter 3.5 on determining the research question. They can also be considered alongside other published, and well-established, recommendations for conducting economic evaluations *(2, 32-36)*.

**Step 1:** Define a research question (see also Chapter 3.5) which:

- identifies the population involved;
- outlines the costs and consequences of the compared courses of action over an appropriate time horizon;
- defines the analytic perspective and decision-making context.

**Step 2:** Describe the interventions and identify any that were not considered, such as specific interventions for population subgroups (see also Chapter 3.3).

**Step 3:** Establish the effectiveness of the intervention or policy. Note how data were synthesized and any factors that may influence the reliability of primary data. If no primary data are available, researchers could draw upon relevant evidence syntheses, such as a systematic review and meta-analysis, to inform estimates of effectiveness (see also Chapter 2.6).

**Step 4:** Describe the relevant costs and consequences for each alternative intervention or policy.

**Step 5:** Measure relevant inputs, for costs and consequences, using appropriate and comparable units. Justify the included measures and their information sources.

**Step 6:** Estimate values for costs and consequences. Record the source of these values and whether they are market values (such as specified drug costs), or non-market values (such as unpaid work) and if values were adjusted, this is often done to account for differences between costs that healthcare providers actually incur, versus the amount they charge.

**Step 7:** Adjust estimates of costs and consequences to account for their changing value over time. This is also known as discounting. Discounting involves individuals placing a lower value on a future cost or consequence versus an immediate one, such as a health benefit today versus one obtained five years in the future. Recommended discount rates vary between countries and organizations. It may also be appropriate to first adjust for inflation, which is the rate of change in average prices over time.

**Step 8:** Compare the costs and consequences of different interventions by combining estimates using an established analysis method. Examples include the incremental cost-effectiveness ratio used in a cost-effectiveness analysis or net benefit used in a cost-benefit analysis.

**Step 9:** Describe uncertainty in estimates of costs and consequences by:

- analysing statistical variance within population level estimates (if available);
- accounting for heterogeneity in results between different population subgroups (if applicable);
- assessing the effect of altering the values of inputs to measures of costs and consequences on overall study findings (via sensitivity analysis).

**Step 10:** Describe results and discuss:

- basing conclusions on an overall index (such as a value in US dollars) or ratio of costs and consequences (such as cost-effectiveness ratio);
- differences between the methods and findings of the study with those in comparable studies;
- the generalizability of results to other settings and populations;
- important factors influencing decision making, such as equity implications;
- wider resource implications, such as budgetary impacts;
- implications of any uncertainty in the study's findings, including the need for future research.

### 4.7.11 Research limitations

Evidence gaps and methodological challenges have limited the prevalence and use of evaluations of economic impacts in Health EDRM research. Reviews of research on infectious disease outbreak preparedness and the impacts of extreme weather events have identified several gaps in economic evidence *(18, 37–38)*. These gaps include a lack of studies that incorporate economic evaluations (most are economic impact studies), use a societal perspective for economic outcomes, or are set in low- and middle-income countries. Addressing evidence gaps is important, especially for those populations that are expected to suffer most from increasing hazard risks, such as heat stress in South Asia *(39)*.

Researchers often use different methods, or adapt methods to their needs. These actions can limit the ability of others to compare the findings of a study with otherwise similar studies. However, from the researchers perspective, it can be difficult to strike a balance between adhering to standardized approaches (to ensure comparability across different economic studies) and adapting to constraints (because of the availability of data, research aims, and resource limitations).

Methodological challenges include attributing outcomes to interventions, measuring the economic value of outcomes and accounting for how preferences for outcomes vary over time. Addressing these for Health EDRM can draw upon research areas with similar methodological challenges, such as economic studies of public health activities and of natural environment interventions *(40–42)*.

- **Attributing outcomes:** In many circumstances it may not be feasible to use a randomized trial (see Chapters 4.1 and 4.3) to attribute and measure outcomes associated with interventions in Health EDRM. This increases the difficulty involved in conducting a robust economic evaluation. However, if sufficient data can be collected, researchers may be able to create a quasi-experimental study (see Chapter 4.5) by using natural variation in people's exposure to interventions.
- **Measuring economic outcomes**: It is difficult to measure different stakeholders' preferences for health and non-health outcomes and to create a combined measure of economic outcomes. Population preferences for these outcomes may also change over time and need to be accounted for. Future research may expand the scope of existing measures, such as recent efforts to adapt the QALY approach to better account for broader wellbeing *(43)*.
- **Time variance:** It is important to consider how to apply discount rates in economic studies in Health EDRM, given the potential (in) frequency of a given health emergency or disaster. A discount rate accounts for the difference in stakeholder preferences for an outcome today versus one in the future, as well as uncertainty and the time value of money, and discounts the expected value of an intervention appropriately. Recommended time horizons and discount rates are available for specific contexts and uses, but there is persistent debate on the most appropriate values to use *(44–45)*.

### 4.7.12 Conclusions

Researchers use economic evaluations and economic impact studies to identify and explain the costs and consequences involved in policies and programmes that support Health EDRM. Practitioners and policymakers can then use the evidence generated by these studies to guide their decision making on specific issues and broader strategic planning.

Established methods and concepts are available to researchers to synthesize and improve the current evidence base of economic studies, although there are challenges to expanding research in this area. Nevertheless, there are opportunities for economic studies to fill knowledge gaps and to address the ongoing needs of decision makers. Researchers and stakeholders can use these opportunities to advocate for putting greater effort into assessing and addressing the economic aspects of past, present, and future health emergencies and disasters *(46)*.

## 4.7.13 Key messages

- **Evaluating economic impacts in Health EDRM can inform and improve prevention, preparedness, response and recovery activities.**
- **Economic evaluations and economic impact studies are established ways to evaluate the impacts of interventions and events. Researchers can draw upon standardized methods and knowledge built by existing communities of expertise.**
- **Current research gaps mean that researchers have the opportunity to develop specific guidance on how to examine economic outcomes in the context of Health EDRM and to conduct more research that incorporates economic evaluations, uses a societal perspective for economic outcomes, and is set in low- and middle-income countries – all of which can offer useful and usable information to improve Health EDRM practices.**

## 4.7.14 Further reading

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# 4.8

# Geographic Information Systems

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## 4.8.1 Learning objectives

To understand the following about geographic information systems (GIS):

1. The basics of GIS.
2. The role of geospatial analysis in disaster health.
3. The use and challenges of GIS in Health EDRM.

## 4.8.2 Introduction

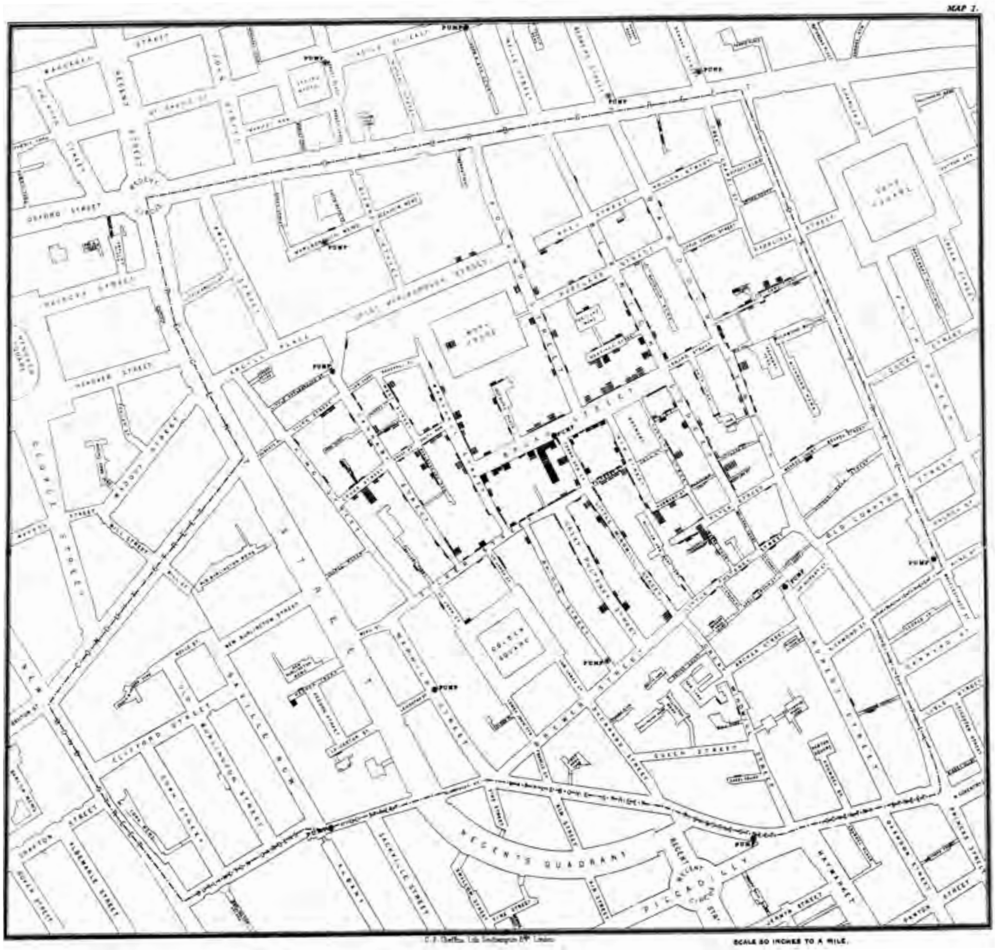
"Location, location, location" is the real estate agents' mantra, emphasizing the overwhelming importance of location on home values. This also provides a framework for the first three questions that should be asked when any disaster occurs, no matter whether it is an earthquake, typhoon, flood or something else. The first question, usually asked by everyone, is *Where has it happened?* The second question, asked mostly by those affected, is *Where are the shelters?* The third question, which is often asked by government emergency management officials, is *Where are the resources?*

The idea that place and location can influence health and safety is old and familiar in many countries and across different cultures. For example, since ancient China, Feng Shui wisdom has offered the understanding that there are a wide variety of energies in different environments, and a variety of Feng Shui methods have been developed for finding places to protect humans and their dwellings from low and attacking energies. In western history, as far back as the time of Hippocrates in the 3rd century BC, physicians have observed that certain diseases seem to occur in some places and not others. More importantly, the spatial nature of epidemiological data has long been understood and used as scientific evidence to support the development of policies to protect and improve human and animal health. In 1854, a cholera outbreak in the Soho district of London, United Kingdom, killed nearly 600 people in just ten days. John Snow, a London physician, identified a contaminated water pump by mapping the locations of water pumps and the homes of people who died of cholera (Figure 4.8.1). After instructing the authorities to remove the handle to the pump, the number of new cholera cases dropped dramatically.

# 4.8

In the modern digital era, people encounter features of geographic locations (such as parks, bus stops, schools, hospitals, police stations and so on) every day. This is also important for Health EDRM, where emergency preparedness and health risk reduction are essentially spatial problems. With the help of new information technology including remote sensing, computers and the internet, all location-based information can be now visualized. Moreover, based on analysis and interpretation of this information, people can better understand relationships, patterns and trends of various components in social-ecological system. This chapter introduces the general concept of GIS, outlines areas of current application in disaster health and discusses future developments.

**Figure 4.8.1 John Snow's cholera map**



A contaminated water pump in Broad Street proved to be the source for the spread of cholera.

Map drawn by Dr John Snow in approximately 1854; shown in Stamp, LD. 1964. A Geography of Life and Death. This redrafting leaves out some interesting bits of evidence that appeared on the original map, and in Tufte's version. For instance, there was a building across the street from the pump that had no deaths at all.

### 4.8.3 What is GIS?

There are many working definitions for GIS. In this chapter, GIS is defined as "a computer system that incorporates hardware, software, and infrastructure for capturing, manipulating, integrating, interrogating, modelling, analysing, and visualizing all forms of geographically referenced information."

GIS have developed rapidly in recent years, providing powerful tools for policy support in a wide range of areas on almost all geographic and administrative levels. For different users, the effectiveness and success of GIS-based applications depends on the hardware, software, technicalities of its implementation and data quality. The design and upgrading of GIS have a close and two-way relationship with the host organization.

### 4.8.4 GIS hardware

In general, a complete GIS system comprises individual computers, computer configuration and networks, input devices, storage systems, output devices (such as 3D printers) and virtual reality display systems. It should be emphasized that computers for GIS usage can be mobile telephones and personal computers at the low end, or supercomputers and X-Terminals at the high end. Hardware requirements vary considerably depending on the tasks undertaken.

### 4.8.5 Software

The choice of software depends on the needs of the organization, the functionality desired and the money available, as well as the period during which the system is planned. There are many high quality and widely used proprietary software applications on the market, which should be compared for their costs and benefits before a particular system is chosen. To date, there are five generations of software have been developed: desktop GIS, Web GIS, GIService, Cloud GIS and Smart GIS.

The development of desktop GIS extends the GIS applications to geographic data management, analysis and visualization. Web GIS is the most used by the general public, and includes products such as Google Earth and Google Map. It allows global access to geospatial data with low barriers for using GIS software in many disciplines, thus delivering real-time data and enabling collaborative data collection and mapping across platform. GIService combines functions of GIS and Web Service. Cloud GIS helps users make better use of the power of cloud computing to provide powerful capability in storage, computation and network. Smart GIS will not only make GIS available everywhere, all the time, and for everything but will also make everything as service.

A summary of different open-source and ESRI GIS programs, showing their capabilities and functionalities is available online *(1)*.

### 4.8.6 GIS Database

The database is the heart of any GIS application project. The development of a GIS-based database is the first step of the project, which involves a process of data acquisition, data digitization, data modelling, and data quality assurance and quality control (QA/QC).

Data acquisition is the GIS-related information acquired in the research project area, usually including data on the ecosystem, climatology, geology, hydrology, land form, soil, and social-economy, as well as other specific information. The data are usually comprised of satellite images, hard copy maps, ground observations and data obtained from the literature.

Data digitization is the process of transforming acquired data from a variety of data formats (such as images or drawings) to a relatively standard data format such as vector and raster:

- Vector consists of features such as point, line and polygon, and is usually stored as a shape file.
- Raster consists of grid cells and pixels which can be stored as images and TIN. After this process, new data will have the same coordinates system, projection, and datum, which can be readily used by GIS software for data analysis.

Data modelling is the process of using the available data to derive additional types of data. For example, the Digital Elevation Model (DEM) and river shape files are used to derive slope, aspect and watershed.

Data QA/QC is the process of validating the GIS data transformed from different sources. Transformed data is validated by comparing the geographic coordinates of pre-determined locations to the field survey results.

#### Case Study 4.8.1
#### Map of health vulnerability and disaster risk *(2)*

To measure the health vulnerability of each country, three factors were captured from nine health indicators for the 147 countries along the Belt and Road region *(2)*: population status, disease prevention and coping capacity. Population status is related to proportion of the population aged under 15 or over 65 years of age, the mortality ratio for children under 5 years and the maternal mortality ratio. The most vulnerable countries were Sierra Leone, the Republic of Chad and the Central African Republic. Ukraine was shown to be the least vulnerable among all of the studied countries. For the second factor, disease prevention, which is related to coverage of the measles-containing-vaccine first-dose (MCV1) and diphtheria tetanus toxoid and pertussis (DTP3) vaccines, the Republic of Equatorial Guinea and Ukraine are prominent, because they had low MCV1 and DTP3 immunization coverage. For the third factor, coping capacity, which is related to physician ratio and hospital bed ratio, Thailand, the Solomon Islands and Indonesia were at the top of the scale. After combining the three factors into a health vulnerability index, Greece, the Republic of Korea and the Republic of Belarus were the three least vulnerable countries, whereas countries in Africa, including the Federal Republic of Somalia, the Central African Republic and Chad were the most vulnerable.

As disaster risk is a function of exposure, hazard and vulnerability, the top five areas with the highest disaster risk identified in this study were in locations near the Philippines, the Islamic Republic of Afghanistan, Bangladesh, Somalia and Indonesia. Northwest China, North Africa, eastern Europe and Australia were found to have relatively lower risks.

The most common usage of the GIS-based database is to quantify research objects' spatial distributions as shown in Case Study 4.8.1. The distribution of any phenomenon or indicators on the earth's surface (geographically) is called spatial distribution. As shown in this case study, mapping various selected factors, allows the health vulnerability of the country to be shown visually to answer the question "what is where?".

As stated in Tobler's First Law of Geography, "Everything is related to everything else. But near things are more related than distant things". Understanding the spatial correlations of various factors in a research region is another important application of the GIS-based database. Exploration of spatial data involves the use of statistical methods to determine whether observed patterns are random. Visualization is the most commonly used spatial analysis method, resulting in maps that describe spatial patterns as shown in Case Study 4.8.2. Models might also be used to study cause-effect relationships, to explain or predict spatial patterns.

### Case study 4.8.2
### Chikungunya in Latin America

Transmission of Chikungunya virus became rapidly established during 2014 in Latin America in places where dengue and its main vector, Aedes aegypti, were present. This 2014 outbreak was the start of a new endemic disease, meaning that in the countries which faced this new arboviral disease, some areas saw stabilization of its transmission with decreased incidence, while others observed a significant increase during 2015. This was the case of the Coffee-Triangle region in Colombia.

In this setting, travellers to endemic areas in Latin American countries should be aware of the risk of infective biting exposure. In order to provide advice to travellers, epidemiological maps for Chikungunya virus were developed using GIS for the Coffee-Triangle region, which is a tourist area with three departments (Caldas, Quindı́o and Risaralda) and 53 municipalities.

Use of GIS-based epidemiological maps allows the integration of preventive and control strategies, as well public health policies for control of this vector-borne disease. For example, preparedness on Chikungunya virus for healthcare workers and students in the region have increased through intense continuing education activities, including community participation on vector control for the purpose of controlling and mitigating the effects of Aedes transmission on Chikungunya virus. Because travellers might also spread the virus, GIS maps also provide relevant information to assess the risk of travellers going to specific destinations with high transmission rates. This allows prevention advice to be made available for both government officials and the general public.

### 4.8.7 GIS Application in disaster health

Any disaster event creates a significant short-term spike in the demand for emergency services, which will require extraordinary measures. As reported by UNDRR *(3)*, the number of natural, accidental, and intentional disasters is growing globally and is an increasing concern for governments, healthcare organizations and the public. Many research studies, in a variety of countries and regions, have shown how the appropriate use of GIS can enhance the effectiveness of the disaster risk management system, thereby safeguarding the population and the community infrastructure. Much of the responsibility for emergency medical response to emergencies and disasters rests on the healthcare sector, but other sectors need to be involved as well and one of the distinctions of disaster health is its multidisciplinary nature.

In high-income countries, many hospitals and other health care facilities are equipped with new information technologies (IT) such as wireless local area networks (LANs) with disaster medical response capabilities including personal digital assistants, tablets and handheld personal computers. Unfortunately, many disaster events overwhelm or destroy the medical infrastructure by damaging hospitals, limiting emergency supplies and closing medical clinics. Taking advantage of recent advances in IT, hospitals and disaster relief agencies could work together using GIS to develop better plan for disasters.

Studies show that when disasters strike, a comprehensive disaster medical response plan with state-of-the-art IT is essential. This needs to ensure that adequate personnel, supplies, equipment and protocols are established to meet potential threats and are at the correct scale to meet the level of the disaster.

During pre-disaster stages, Health EDRM needs accurate public health data on air, water, sanitation, utilities and community healthcare facilities. Moreover, geo-referenced baseline demographic data and health area boundaries are also important. During a disaster, healthcare organizations need to have an acceptable surge capacity, so that they are able to expand beyond normal service levels to meet an increased demand for medical care. One example of building surge capacity is the development of a national real-time, hospital-bed tracking system named the National Hospital Available Beds for Emergencies and Disasters (HAvBED) system in the USA. The system includes a GIS, established communications protocols, a database and standardized hospital bed definitions.

It is also critical to track patients and essential medical supplies in both pre-disaster and post-disaster phases, as well as during a disaster. A related planning tool is the Emergency Preparedness Resource Inventory, which is a web-based tool that can assess the regional supply of critical resources, prepare for incident management, identify deficiencies in services, and support resource acquisition decisions. The Emergency Preparedness Resource Inventory also includes an inventory checklist to record where emergency equipment and medicines are located, the amount on hand, and how to obtain additional supplies.

GIS can also provide real-time tracking of people both patients and healthcare personnel. Tracking patients during a disaster helps with improved care, family notification and the allocation of emergency services.

This type of technology can help first responders to locate patients during emergency response and transfer patients when hospitals are full, then assist in coordinating patient care as individuals are moved during the emergency care process; as illustrated in Case Study 4.8.3.

**Case Study 4.8.3**
**Health risk distribution of people with high temperature disasters *(4)***

Global climate change is increasing the frequency of extreme weather events, which have substantial impact on human health and social economy *(5)*. As an important type of extreme weather event, extreme summer temperatures have been widespread throughout the world and will continue to increase in frequency, extent and duration *(6)*. High-temperature disasters caused by high summer temperatures directly affect human health. In 1995, the heatwave in Chicago in the USA and the heatwave in Europe in 2003 caused a large number of deaths *(7–8)*. Excessive summer temperatures will increase the incidence of cardiovascular, respiratory, digestive tract and other diseases. High temperature weather will also lead to environmental pollution caused by the accumulation of harmful gases and smoke, further threatening human health *(9)*. However, targeted space control measures such as high-temperature warnings and resource allocation can minimize expected risks. People with different characteristics have different resistance to high temperatures. Therefore, the identification of vulnerable populations and health risk assessment of high-temperature disaster populations are important for targeted disaster prevention and mitigation and resource allocation *(10)*.

Based on the disaster risk assessment framework proposed in the fifth research report of IPCC *(6)* , a conceptual model of “high temperature stress-social vulnerability-population exposure” for population health risk assessment based on high temperature disasters; combined with meteorological data, remote sensing data, and socio-economic statistical data, the GIS and RS platforms have been used to complete the high-temperature disaster risk assessment at the country level. The results show that the hot spots of high temperature disaster vulnerability are mainly distributed in underdeveloped areas, with high temperature stress or poor social economy.

## 4.8.8 Challenges

Many studies show that healthcare organizations that invest appropriately in IT, including GIS, can improve the quality and efficiency of their healthcare services. In particular, when these investments are incorporated into disaster plans, it leads to benefits for emergency medical response and to other aspects of Health EDRM. However, there are concerns about the safety of the data which GIS collects, stores, analyses and displays; as noted in Case Study 4.8.4.

### Case Study 4.8.4
### GIS for population-wide health monitoring in the Federal Republic of Germany

In recent years, GIS have become an integral part of public health research. They offer a broad range of analysis tools, which enable innovative solutions for health-related research questions. An analysis of nationwide studies in Germany that applied GIS underlines the potential of GIS for health monitoring in Germany. GIS provide up-to-date mapping and visualization options to be used for national health monitoring at the Robert Koch Institute (RKI). Objective information on the residential environment as an influencing factor on population health and health behaviour can also be gathered and linked to RKI survey data at different geographic scales. Besides using physical information, such as climate, vegetation or land use, as well as information on the built environment, the instrument can link socioeconomic and sociodemographic data to information on health care and environmental stress with the survey data. This allows integration of the data into concepts for analyses. In this way, GIS expands the potential of the RKI to present nationwide, representative and meaningful health-monitoring results. However, in doing so, data protection regulations must always be followed. This balance of the safety of the data with the development of a national spatial data infrastructure and the identification of important data sources that can improve access to high quality data sets relevant for the health monitoring, is an important element in the development of this GIS.

Another challenge associated with implementing GIS in a robust medical disaster response plan is the cost associated with many of the necessary tools. In order to better serve their patients, continuous financial support for accurate, update and sufficient information is needed by healthcare organizations. This is particularly significant in rural US and in low-income countries. The level of regional, national and international efforts to manage disasters also urgently requires a coordinated GIS-based approach that connects local, state, and national emergency programs.

The third challenge to disaster medical response is the effective use of multiple data sources to develop a coordinated management approach *(11)*. The use of wireless LANs, GIS technology, patient-tracking systems and online medical resource databases will improve disaster medical response including early disaster event detection, outbreak management, connecting laboratory systems, response administration, communications and public health alerts; but will need good coordination. These technologies will improve patient care and safety, as well as provide for better command and control, leading to more efficient resource utilization. However, GIS will only make a powerful contribution if they include reliable and representative underlying baseline and situational data. The quality of these data needs to be carefully considered while interpreting the results. To help users better understand the complex situation, the choice of the GIS visualization method (for example, colour or grouping of the variables in a map) can also affect the overall interpretation of the situation.

## 4.8.9 Conclusions

GIS technology is expanding its application into Health EDRM, covering and going beyond disaster health risk detection, modelling, assessment, response planning and public health policy development. The development and maintenance of disaster health management systems based on GIS, however, not only depend on technology but also involve many components in a complex social-ecological system. Multi- and trans-disciplinary trained professionals equipped with relevant information technologies are crucial to meet the current and future challenges of using GIS in disaster health science.

## 4.8.10 Key messages

- **A main strength of GIS lies in its powerful ability to combine, analyse and display spatial and attribute data.**
- **This will help to satisfy the need for large-scale data analysis and processing in disaster response planning and improve Health EDRM.**

## 4.8.11 Further reading

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# 4.9

# Real-time Syndromic Surveillance

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## 4.9.1 Learning objectives

To understand the key factors underpinning real-time syndromic surveillance systems and the use of syndromic surveillance data in research, including:

1. The definition of syndromic surveillance;
2. Data sources for syndromic surveillance;
3. Governance issues;
4. Data analysis and statistics;
5. The application of syndromic surveillance in research.

## 4.9.2 Introduction

Syndromic surveillance is the near real-time collection, analysis, interpretation and dissemination of health-related data in order to enable the early identification of the impact (or absence of impact) of potential health threats that may require public health action *(1)*. Although a relatively new field in comparison to more established methods of surveillance (such as using laboratory reports), syndromic surveillance is growing in stature internationally as it becomes recognized as an innovative approach to public health surveillance. The advantages that syndromic surveillance brings to the identification and investigation of public health threats, including those relevant to health emergency and disaster risk management (Health EDRM), include early warning, situational analysis, reassurance and flexibility.

**Early warning**
Many syndromic surveillance systems operate in near-real-time (daily, for example), allowing the timely identification of, and response to incidents.

**Situational awareness**
During an incident, syndromic surveillance systems enable further description of healthcare seeking behaviour in near real-time (daily, for example) providing key intelligence to incident managers and response teams (such as identifying particularly affected age groups, geographical clusters).

**Reassurance**
During mass gatherings and other similar events, syndromic surveillance can often provide reassurance that there have been no widespread acute public health problems, particularly where surveillance is long term and a 'normal' or historical baseline level has been established prior to the event.

**Flexibility**
By using broad and adaptable syndromes, syndromic surveillance systems can be flexible in responding to a variety of public health demands ranging from infectious disease outbreaks to environmental incidents and mass gatherings, in addition to providing measures of impact of public health interventions – vaccination impact, for example. Syndromic surveillance also has the potential to detect newly emerging threats not covered by existing surveillance systems.

In general, syndromic surveillance makes opportunistic use of anonymized data collected either as part of standard patient care from healthcare service providers, or proxies of population health (for example, information on accessing of health advice from other sources; see also Chapter 2.1). This information is collected by the healthcare provider or advisor, usually during the contact with the patient and before any final confirmation of a diagnosis or cause of illness. The data used for syndromic surveillance therefore contain valuable detail of symptoms, chief complaints, clinical diagnoses, or other proxies for healthcare seeking behaviour. Furthermore, as this information is collected contemporaneously these data can be made available and used for syndromic surveillance purposes very quickly – often the following day, if not sooner *(2)*.

Syndromic surveillance collates the information received and groups it into syndromes of public health relevance (Table 4.9.1). Each syndrome is constructed from the symptoms, chief complaints or clinical diagnoses, as they have been recorded in the patient record. The format of the data is often data provider specific, based on how information is organized and stored in the local patient record, which may use a standardized coding system, a locally used list of clinical terms or even free text. For example, general practitioners (GPs) managing a patient with acutely presenting asthma use clinical codes (such as ICD-10, SNOMED-CT or Read codes *(3–5)*) to record the clinical management of the patient. Asthma monitored in a syndromic surveillance system would be based on the identification of those patient contacts including clinical asthma codes.

**Table 4.9.1 Examples of syndromic surveillance syndromes that are flexible in responding to a range of public health threats**

| Syndrome monitored | Related public health threats |
|---|---|
| **Asthma** | Respiratory pathogens, air pollution, chemical incidents, wild or industrial fires, severe thunderstorms |
| **Fever** | Influenza, respiratory pathogens, heatwave (infants) |
| **Difficulty breathing** | Air pollution, respiratory pathogens, chemical incidents, wild or industrial fires |
| **Diarrhoea and vomiting** | Gastrointestinal pathogens, flooding |
| **Conjunctivitis** | Respiratory pathogens, chemical incidents, wild or industrial fires, allergic rhinitis |
| **Cough** | Influenza, respiratory syncytial virus (children aged <5 years), respiratory pathogens, chemical incidents, wild or industrial fires |

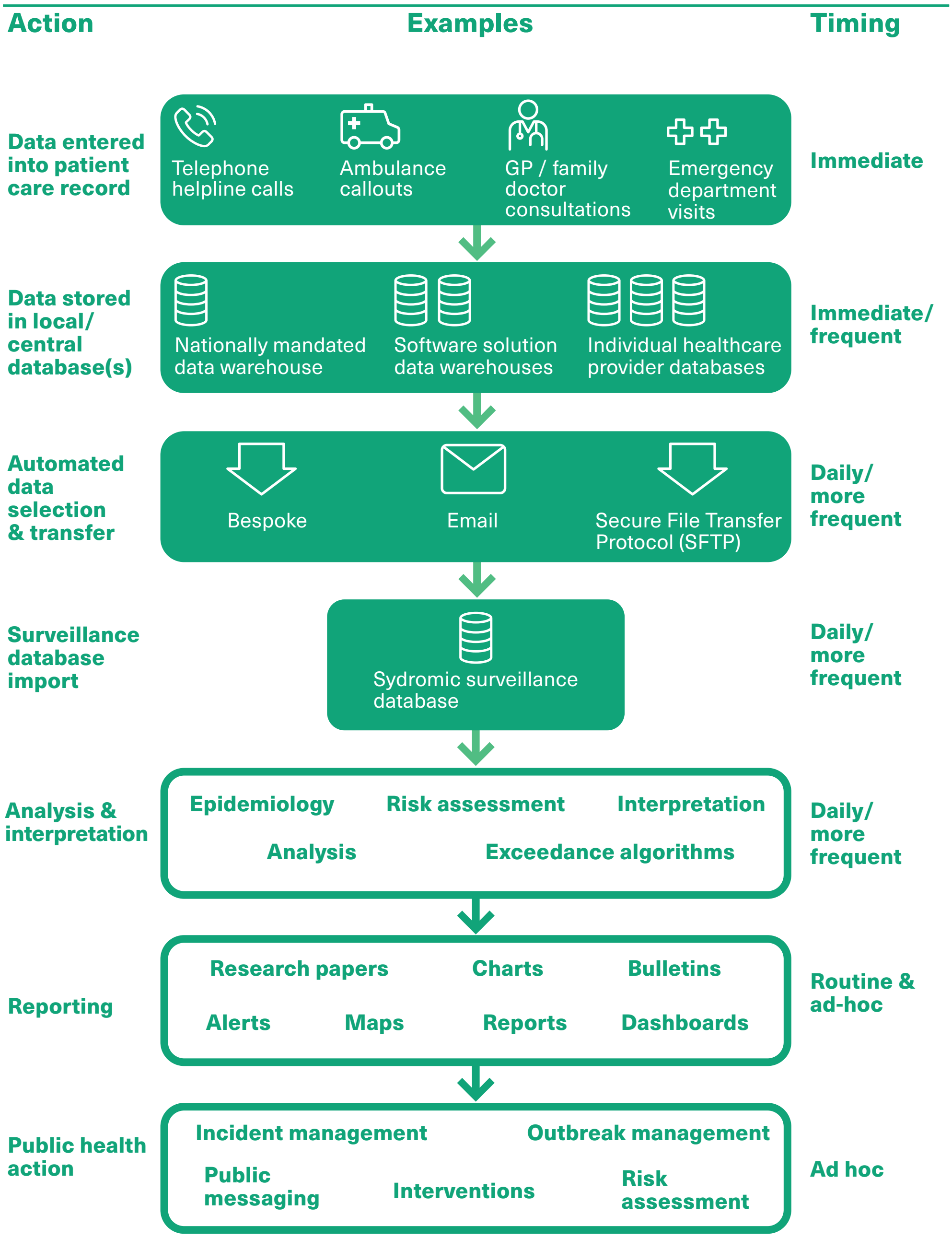
Syndromic surveillance does not generally monitor laboratory confirmed reports. Although a lack of laboratory confirmation (and therefore the absence of a direct link to a causal pathogen) presents a potential limitation in the *specificity* of reporting (particularly around infectious diseases), it can also be an advantage as the flexibility of the systems enables greater *sensitivity* due to the broadness of data collected and the volume of information available. The flexibility of syndromic surveillance systems enables them to respond to a variety of public health incidents, ranging from infectious diseases *(6–7)* to environmental events *(8)*, mass gatherings *(9–10)*, terrorism *(11)*, recovery from disasters caused by natural hazards *(12–13)* or investigations of vaccination impact *(14)*. A single syndrome may be relevant to several different public health issues (Table 4.9.1). For example, a newly emerging respiratory pathogen may not be detected by existing laboratory tests, but increases in numbers of presentations, or severity of illness, in symptomatic patients presenting to healthcare services would be captured by syndromic data.

Syndromic surveillance systems also have the advantage of providing wider population surveillance, covering whole regions or countries, at different levels of patient care (from those requesting advice only, to those requiring urgent emergency treatment), providing a picture of the levels of severity of disease within the community. Laboratory-based surveillance, however, is often biased, based upon only those sampled for testing, which is often limited to patients with ongoing illness, who are more severely ill or hospitalized, or are considered to be at-risk of complications or death. Laboratory surveillance therefore monitors only a fraction of the total burden of disease.

While there are fundamental differences between syndromic and laboratory-based surveillance, it is important that both are synergistic, complementing each other to ensure the delivery of a functioning public health surveillance programme. Without laboratory surveillance, it is difficult to determine the underlying pathogens driving seasonal trends in syndromic data; without syndromic surveillance, it is difficult to establish representative community-based estimates of burden.

The collection of information for syndromic surveillance is normally automated, with electronic transmission of anonymized data from healthcare service providers to public health organizations. Figure 4.9.1 illustrates how health data might flow in a multi-partite syndromic surveillance system. The automation of data collection removes the requirement to ask data providers to undertake additional time-consuming tasks or to remember to flag individual records for inclusion in a syndromic surveillance system. Automation is critical to the success of such systems, especially those based upon healthcare services. Data are collected as part of the usual patient care or advice process. No extra steps or changes to working practices are required by the data providers for syndromic surveillance to be possible.

**Figure 4.9.1 Example data flow for a multi-partite syndromic surveillance service**



Source: Public Health England Real-time Syndromic Surveillance Team.

### 4.9.3 Data sources for syndromic surveillance

Data for syndromic surveillance are commonly sought from a range of healthcare services including primary care providers or GPs, emergency departments (EDs), telehealth services and ambulance services.

**Primary care/general practitioners/physicians/family doctors**
Primary care surveillance is often considered a gold standard for assessing community morbidity. Syndromes are usually constructed using clinical diagnoses as recorded by the treating physician at the time of the consultation.

**Emergency departments**
EDs are frequently used for syndromic surveillance, particularly in countries where access to primary care data may not be readily available. ED surveillance provides a metric for more severe presentation of disease or conditions. Syndromes may be constructed from chief or presenting complaints, or clinical diagnoses, depending on the timescale at which the information is available.

**Telehealth services**
Telehealth surveillance can provide access to populations not captured through ED or primary care surveillance, such as those who are less ill and require advice, rather than urgent care. Traditionally considered to provide early warning over other systems, the syndromes used are based on patient reported symptoms and may have the lowest specificity.

**Ambulance services**
Monitoring ambulance dispatch calls can provide an additional measure of acute, potentially more severe presentation of diseases or conditions in public health surveillance.

Outside the healthcare setting, many additional data sources have been used for syndromic surveillance. School absenteeism, employee absenteeism and over the counter pharmacy sales are examples where data represent proxies for disease. These sources have been usefully adopted for monitoring the health of the population *(15)*.

In recent years, with the advent and increasing use of digital platforms to access healthcare and advice, more public health resource has focused on assessing the potential benefits of using ‘digital data’ such as web searches (such as Google *(16)*), social media activity (such as Twitter *(17)*) and online health services (an online ‘symptom-checker’, for example *(18)*). The methods used for accessing and collecting data continue to develop, evolving from platforms such as messaging services (for example, HL7 *(19)*) to techniques suited for trawling big data (for example, data mining or natural language processing *(20)*.

## 4.9.4 Governance

Although it is often overlooked in the published syndromic surveillance literature, the adherence to good governance and data security practices around the collection, storage, processing and use of healthcare data for syndromic surveillance is important. Establishing a syndromic surveillance system (either at national or subnational level) requires multiple phases undertaken by a multi-disciplinary group. This has previously been described by experienced exponents of syndromic surveillance *(1)*. However, one of the key areas that will determine the sustainability of a system is establishing appropriate governance arrangements with data providers to assure the correct use and secure storage of data, as well as the competence of trained specialist staff accessing, analysing and interpreting data. Without such assurances, data are unlikely to be made available for syndromic surveillance.

The governance arrangements underpinning syndromic surveillance systems are equally essential for the long-term success of systems. Without appropriate governance, these surveillance systems are not fit for purpose and are likely to fail. Alongside governance, appropriate management and oversight of syndromic surveillance systems is important for their success, with collaboration between data providers and public health intelligence teams to steer the development and management of the systems. Management through steering or strategic groups, including senior members from all organizations involved in delivering the system is crucial to long term success, fruitful outputs and assurance of the public health benefits of the surveillance system. Collaboration may involve a wide range of organizations including data providers, technology firms providing data collection or transfer systems, public health bodies, clinical groups, academics and professional bodies. Furthermore, these steering groups might be used as a conduit to ensure that research undertaken using the syndromic surveillance data is appropriate (that is, with a public health focus), undertaken with appropriate rigour and, most importantly, that it does not undermine any organization involved in the collaborative surveillance system.

## 4.9.5 Analysis of syndromic surveillance data

There are many methods used to routinely analyse syndromic surveillance data. The underlying principle of syndromic surveillance is the analysis of trends, rather than identifying individual cases. Traditional descriptive epidemiological methods can be used to examine patterns in disease over time, by person and place, and formal statistical tests can be used to detect anomalies (Figure 4.9.2).

**Time**
Syndromic surveillance data are analysed over time to identify short term increases in syndromes (suggesting outbreaks of disease, for example), environmental impacts (air pollution, for example) and long-term changes in trend (suggesting changes in disease burden).

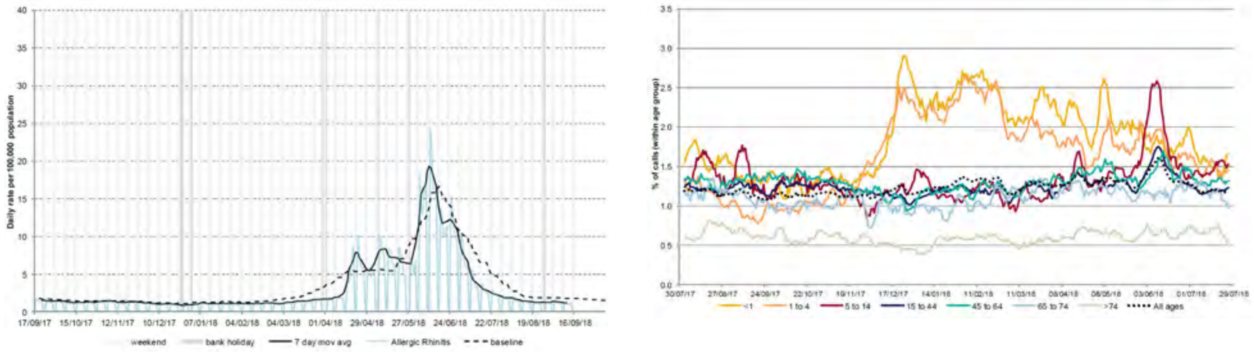
**Person**
Data can be broken down by patient demographics (such as age or gender) to identify changes in burden, which may be indicative of public health threats.

**Place**
Where possible, links to the location of the patient (either area of residence or place of healthcare consultation) can be used to identify clusters or map the spread of activity.

**Anomaly detection**
Statistical algorithms are used to automatically identify unusual activity. Statistical tests can also be used for anomaly detection or aid interpretation of syndromic data. A wide range of different statistical methods have been used for anomaly detection, including control charts, regression and time series analysis *(21–22)*. Statistical methods can also be applied to the development of historical baselines, which can supplement the interpretation of syndromic data by comparing the observed values to historically expected levels *(23)*.

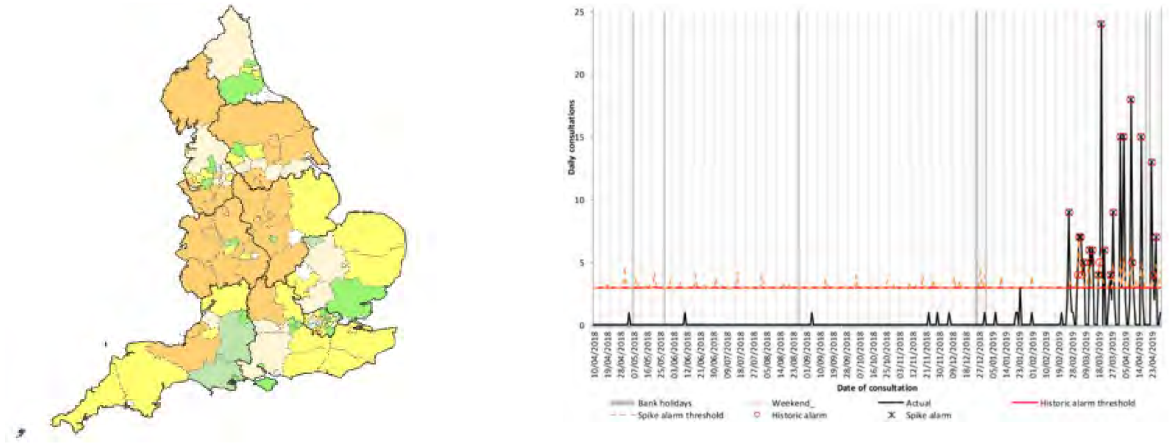
A further important consideration is the translation of complex information (as produced by epidemiological or statistical analyses) into public health action, a core component of the definition of surveillance *(24).* This element of syndromic surveillance is not well described in the literature but there are examples available of risk assessment processes designed to assess statistical exceedances by examining relevant epidemiological information and assigning an appropriate response – for example, whether no further action is required, or whether the information needs to be sent to a relevant public health expert for further action *(25)*.

## Figure 4.9.2 Analysis of syndromic surveillance data using A) time, B) person, C) place and D) anomaly detection



**A. Time:** daily GP consultation rate for allergic rhinitis

**B. Person:** telehealth calls for eye problems by age group



**C. Place:** map of GP consultations for influenza-like illness (England)

**D. Anomaly detection:** daily statistical exceedances for mumps

Source: PHE Real-time Syndromic Surveillance Team
Map contains Ordnance Survey data. ©Crown copyright and database right 2018. Contains National Statistics data.

### 4.9.6 Using syndromic surveillance in research

The collection of health data to deliver real-time syndromic surveillance can provide a rich resource for Health EDRM researchers to address important public health questions. Alongside the use of other sources of public health data, a wide range of research methods outlined elsewhere in this book can be used alongside syndromic surveillance data. However, syndromic surveillance data are not collected specifically for research purposes and therefore when considering the use of syndromic surveillance data in research, it is important to understand several key limitations of these data, which might limit their application in certain research projects (Table 4.9.2).

**Table 4.9.2 Limitations of syndromic surveillance data that need to be assessed when considering its use in research projects**

| Limitation | Detail |
|---|---|
| **Anonymized records** | Syndromic data tend to be anonymised and therefore patient-level data cannot be linked to other records or databases and cannot be used to trace patients or undertake further studies (for example, selecting controls for case-control type analysis) |
| **Population level** | Syndromic data tend to be aggregated to population level and often cannot be used for secondary analyses on an individual level |
| **System coverage** | Some syndromic systems do not have full or representative coverage geographically (country or region), or person level (such as different age groups: paediatric or adult EDs) or other limitations on access to healthcare |
| **Coding** | Clinical coding used to define syndromes can be limited or very generic or, if free text is provided this might require additional analytical skills |
| **Symptom based** | Syndromic data are not based on confirmed laboratory reports and, therefore, are not directly attributable to specific pathogens |
| **Data quality** | Syndromic data are not 'cleaned' before being used for surveillance. Consequently, compared to other health data sources used by researchers, there is a greater risk of data errors (for example, duplications, miss-entry of age data, incorrect coding or incomplete data fields) |
| **Incomplete data** | Syndromic data only uses data available in real-time, taking a 'snapshot' of daily activity. Therefore some data will be excluded due to transfer issues or time taken to confirm diagnoses. For example, most GP pneumonia diagnoses occur after laboratory confirmation and are not available in a next-day extract. |

Case Studies 4.9.1, 4.9.2 and 4.9.3 describe examples of published research projects where syndromic surveillance data have been used to respond to a public health problem.

### Case Study 4.9.1
### Assessing potential health impacts of mass gatherings and sporting events *(26)*

Mass gatherings can impact on the health of the public, including both infectious and non-communicable diseases or conditions. Specifically, the increased risk from infectious diseases includes importation, exposure of visitors to endemic diseases in the host country and increased disease transmission across large populations gathered in one location. Surveillance during mass gatherings is needed to identify and quantify any impact (or reassure that there is an absence of impact) on public health in a timely manner. Subsequently, research on specific areas following an event can inform priorities for healthcare providers and public health organizations at future events.

Large sporting events (for example, the Olympics or world or continental football championships) have the potential to influence the behaviour of the population, and increase (or decrease) demand on health services around the timings of individual events. Of particular note, the impact of sporting events on ED attendances has been documented *(26)*. The 2016 European Football Championship (Euro 2016) was hosted in France, involving 24 nations with 51 matches during a four-week period. To assess the potential impact of Euro 2016 on healthcare seeking behaviour in different nations, syndromic surveillance ED data from four participating countries (England, France, Northern Ireland and Wales) were analysed retrospectively to identify any relevant impacts of matches played. This study focussed on hourly ED attendances across each country. In the four hours before matches were played by the national team, attendances were statistically significantly lower than would be expected in all countries, and reduced further during matches. Following the completion of matches, there was no consistent significant increase in attendances. However, these observed impacts were highly variable between individual matches. For example, in the four hours after the final match, involving France, the number of ED attendances in France increased significantly. Overall, these results indicated relatively small impacts of major sporting events upon ED attendances.

### Case Study 4.9.2
### Assessing the impact of air pollution on health using syndromic surveillance *(27, 28)*

Globally, air pollution is the biggest environmental risk to health, carrying responsibility for about one in every nine deaths annually. It is estimated that 91% of the world's population lives in places where air quality exceeds WHO guideline limits *(29).* Syndromic surveillance systems present an opportunity to assess the acute impact of air pollution on the health of the population. The utility of syndromic surveillance for this purpose has been demonstrated by the identification and monitoring of healthcare seeking behaviour during periods of poor air quality (air pollution). In this scenario, research involving syndromic surveillance data would require a methodological approach to determine whether existing data collected prospectively over a defined time period can be assessed against air quality data. Different research methods may include using numbers or rates for each syndrome or statistical exceedance data to identify periods of unusual syndromic activity. These events can then be compared to air quality data highlighting periods of poor air quality to identify concurrent activity.

More complex research approaches may incorporate the inclusion of further variables and confounders, which might influence the outcome of the relationship between healthcare seeking behaviour and air quality. For example, meteorological variables (such as temperature), environmental variables (such as pollen and spore counts) or pathogen activity (such as influenza laboratory reports) can all be included in models which explore the relationship between air quality and syndromic data. The results of this research can be used to assure prospective surveillance during air pollution incidents by providing baselines for future interventions and adding to the knowledge base. Furthermore, this research provides information on the specificity and sensitivity of syndromic surveillance systems and uses syndromic surveillance data to explore which pollutants drive changes in healthcare seeking behaviours *(28)*.

### Case Study 4.9.3

### Determining the likely impact of a new vaccine programme using syndromic surveillance *(14)*

Syndromic surveillance can contribute to research investigating the impact of public health interventions, for example, the impact of the introduction of new vaccines on the health of the population. Whilst national vaccination programmes will employ large scale evaluations to assess the impact of the new vaccine on confirmed outcomes, syndromic surveillance can contribute a rapid assessment of the impact. An anticipated outcome of the introduction of a new vaccine might be reduced disease incidence and thus fewer healthcare visits, something which is measured by syndromic surveillance as standard.

Interrupted time series and 'before-after' study methods (Chapter 4.1) can be used to assess the impact of a new vaccine on the demand for healthcare services. These research methods involve measuring the outcome of interest before and after the programme, service or intervention has been implemented. Syndromic data collected before the introduction of the intervention are compared to equivalent data collected after the event. Statistical comparisons of syndromic surveillance data, for example, in pre- and post-vaccine periods, can inform the interpretation of the likely impact of the intervention or vaccine.

In the United Kingdom, rotavirus vaccine was introduced in 2013 and integrated into the routine immunization schedule for young infants. Syndromic surveillance was used to provide an early indication of the potential impact of the introduction of the rotavirus vaccine. Syndromes were chosen based on the anticipated outcome affected by the introduction of the vaccine: GP and ED gastroenteritis, diarrhoea and vomiting syndromes were retrospectively assessed across different age groups, but particularly focussed on young children. Incidence rate ratios (IRRs) were used to compare (statistically) the period of activity pre-vaccine introduction with activity post-vaccine. IRRs showed an approximate 30% decrease in gastroenteritis incidence in infants and children aged 1 to 4 years.

Syndromic surveillance thus revealed a marked decline in gastroenteritis, coinciding with the introduction of the new rotavirus vaccine programme in England *(14)*. This model for contributing to the assessment of the impact of vaccine has been applied to other areas including the live attenuated influenza vaccine *(30)* and meningococcal B vaccine *(31)*, and will be applied to future vaccines as and when they are licensed and introduced (such as respiratory syncytial virus, norovirus).

## 4.9.7 Conclusions

Syndromic surveillance can complement existing public health surveillance programmes, introducing new intelligence for identifying and managing incidents. The flexibility of these systems supports a range of public health issues, including infectious disease activity to Health EDRM. Healthcare service data have traditionally underpinned syndromic surveillance systems, however, novel sources including social media and internet-based data are being explored for their potential added benefit.

## 4.9.8 Key messages

- **Syndromic surveillance systems can augment existing public health surveillance programmes, providing early warning and introducing real-time intelligence and reassurance at a national, regional and local level.**
- **Compared to traditional surveillance systems, syndromic surveillance can provide a more flexible approach to surveillance, enabling multi-purpose surveillance including emerging threats.**
- **Adherence to good governance and data security practices around the collection, storage, processing and use of syndromic surveillance data is essential for the long-term success of systems.**
- **Syndromic surveillance data are a valuable resource for public health research, including in Health EDRM, but specific limitations of syndromic surveillance for research need to be considered.**
- **Syndromic surveillance systems gain value in research data sources when operated consistently over time enabling comparison to historical data.**

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## 4.10

# Using logic models in research and evaluation of Health EDRM interventions

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## 4.10.1 Learning objectives

To understand the following about the use of logic models in Health EDRM:

1. The importance of logic models for research and evaluation in Health EDRM;
2. Methods for constructing and using a logic model to guide research and evaluation projects.

## 4.10.2 Introduction

This chapter outlines how logic models can be used to conceptualize how interventions are intended to work, and their relationship with the broader context in which they take place – focusing on Health EDRM settings. Logic models are tools used to outline assumptions about the chains of processes, activities or events expected to occur during the implementation of an intervention, and the way in which these lead to changes in outcomes. They provide an initial set of assumptions about how different components of an intervention are expected to change outcomes, and can be used to develop further sub-research questions to investigate the validity of these assumptions. Logic models can also be used to communicate findings from research and evaluation activities, and can serve as useful tools in planning an intervention, including for the identification of relevant outcomes and monitoring of its delivery. However, this chapter will focus primarily on the use of logic models for research and evaluation purposes.

### 4.10.3 Why use a logic model in research and evaluation?

Programme theory refers to a number of collaborative approaches that allow stakeholders to work together to identify what should be done about a particular health challenge, how this should be done, and the intended outcomes and impact. A logic model is a framework for programme theory that graphically depicts a series of assumptions or steps about how an intervention is expected to achieve impact.

A logic model provides an accessible way for developing a shared understanding across different stakeholders of what an intervention is intended to achieve and a theory of how this will happen. Although there are several ways in which logic models can be used during the design of research and evaluation studies, they provide a means to explore two issues of relevance to policy makers and healthcare practitioners.

Firstly, logic models help users to theorize how the observed impacts of an intervention reflect factors around the implementation of the intervention and/or to its design *(1)*. For example, an intervention in a flood-prone area that is intended to help people to prepare for a disaster might include raising awareness of what should be included in a household disaster preparedness kit (for example, a torch and a supply of bottled water) *(2–3)*. The intervention as a whole might consist of a series of educational components delivered in community settings and a mass media campaign to improve knowledge of what should be included in the kit. If an evaluation study then found that the intervention did not lead to an improvement in knowledge, a logic model may help the researchers to assess whether this was due to problems with the design of the intervention or with its implementation. Using a logic model in an evaluation study provides a framework for understanding how an intervention works, and for producing evidence that can help to differentiate between an intervention that was not implemented properly and one that was not theorized properly (that is, even though it was properly implemented, it did not have a beneficial effect) *(4)*.

Secondly, using a logic model as the framework for research and evaluation in Health EDRM provides nuanced evidence that can be used to better understand how, where, and among whom the intervention is more likely to succeed *(5)*. For example, if the aforementioned disaster preparedness intervention was found to be successful in a particular setting, a well-specified logic model could be used to design an evaluation to establish if both components (the educational intervention and the mass media campaign) were necessary for success if the intervention were to be implemented elsewhere. Similarly, the logic model might be used to consider whether there were characteristics of the setting or population that facilitated or hindered the success of the intervention.

Chapter 3.3 discusses the design of interventions; using logic models supports researchers and evaluators to consider the factors that make interventions succeed or fail, and how these differ according to the characteristics of the setting or the population. Logic models are therefore frameworks that guide researchers, practitioners and policy makers and inform their decisions through developing theories of what an intervention is trying to achieve and how it will meet this aim.

### 4.10.4 When are logic models used?

Logic models can be used at different stages of an intervention, and by different stakeholders for different purposes *(4,6)*. They can be used from the outset, in the planning and design of an intervention, as a framework to underpin research into what the intervention is attempting to achieve and whether this is likely to be successful. Once the intervention is in place, logic models can be used to support implementation and to monitor and evaluate progress and performance. Although logic models are usually presented in graphical form, they can be presented in other formats; when presented in a tabular format, this may align with a logframe, which can serve many of the same purposes as a logic model, but has been described as more challenging to use for complex interventions *(4).*

For research and evaluation, logic models can be used to guide the overall conduct and design of the evaluation, including as a framework for identifying the questions that should be addressed, the outcomes that should be measured and the data that should be collected. Until recently, as noted in other chapters, the field of disaster medicine has been impeded in its development by a lack of evaluation studies in the peer-reviewed literature *(6)*. Fortunately, there is now greater emphasis on systematically evaluating disasters and emergencies and their impacts across a range of domains, and understanding how different ‘vulnerability, capacity, exposure of persons and assets, hazard characteristics and the environment interact to amplify or reduce losses’ *(7–8)*. The use of logic models in evaluation studies provides a framework for prioritizing and structuring data collection and analysis and ensuring that an evaluation examines the main components of an intervention and the relationships between them.

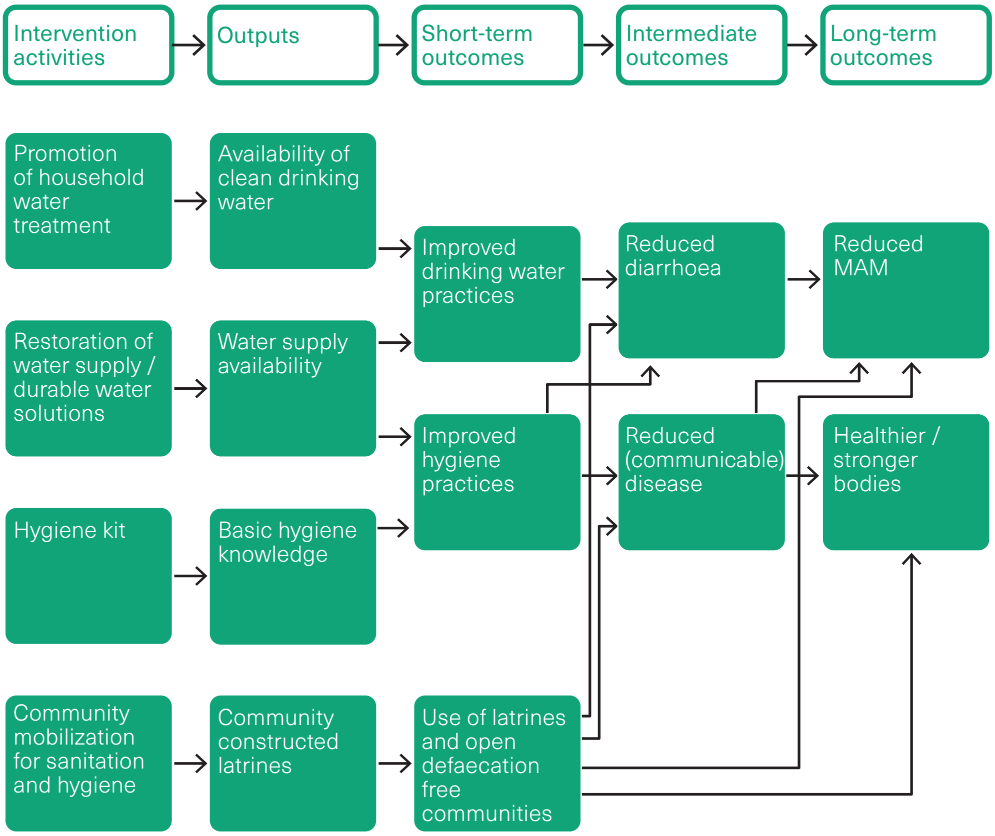
Logic models are also regarded as engagement tools to bring together diverse stakeholders, for example, in allowing them to develop a shared understanding of the priorities and modes of operation of the intervention *(4)*, helping to produce context-specific research knowledge *(9)*, and increasing the likelihood that the results of an evaluation will be accepted and used *(10)*. Logic models are also widely used for communication about evaluation studies *(11)*. Finally, logic models are used in evidence-informed policy and practice when synthesizing evidence from across different studies or settings about the feasibility or impact of a particular intervention approach *(12–13)*, and in making decisions about whether to implement, adapt or innovate a given intervention *(4)*.

Logic models may also be used at different levels, from theorizing how a single intervention might ‘work’ through to theorizing the impact of a suite of interventions forming a large programme. The latter will likely require the development of complicated multi-strand and multi-level logic models that might seek to depict the actions of several different nongovernmental organizations, institutions and other stakeholders. However, across these different purposes, the processes of interpreting and constructing a logic model follow similar principles.

### 4.10.5 Interpreting a logic model

A logic model is a graphical representation of intervention processes and how they change outcomes, depicted as chains of cause-and-effect relationships *(14)*. Figure 4.10.1 is an adaptation of a logic model supporting the evaluation of an intervention to increase community resilience to disaster in Pakistan, and is adapted from the work of Avdeenko and Frölich *(15)*. The logic model depicts a programme theory of how multi-component interventions involving Water, Sanitation and Hygiene (WASH) can increase resilience to disasters and improve health. Focusing in on a single pathway at the top of the model, representing a pathway between the restoration of water supplies and a reduction in levels of Moderate-Acute Malnutrition (MAM), we read the model from left to right as a series of 'if…then…' statements *(16)*. These statements are based on the premise that if 'x' occurs, 'y' will occur, and are used to link different sections of the chain. Reading from left to right, *if* water treatments are promoted, *then* there will be greater availability of clean drinking water. In turn, *if* there is greater availability of clean drinking water, *then* drinking water practices will improve; and *if* there are improvements in drinking water practices, *then* levels of diarrhoea will reduce. Finally, *if* there is a reduction in diarrhoea, *then* levels of MAM will reduce.

**Figure 4.10.1 Logic model for the impacts of WASH activities in improving health as part of interventions to increase community resilience to natural disasters in Pakistan *(15)***



Our reading of the logic model and focus on a single strand is a simplified interpretation of how the intervention may reduce levels of MAM. For example, it is recognized within forms of guidance around WASH interventions (17) that behaviour change is not automatic with the provision of clean water supplies, and should be explicitly programmed alongside environmental, social inclusion and treatment and care interventions. Furthermore, the logic model actually shows five different potential pathways that might lead to such a reduction, all or only some of which may be needed in order for a reduction to be observed *(15)*. Because the model indicates that a reduction in MAM may be achieved through different pathways or combinations of components (known as equifinality), the intervention can be considered to be complex in nature, requiring a particular suite of analytical tools for its evaluation *(14)*.

### 4.10.6 Features of a logic model

Logic models depict often highly complex interventions in a manageable and interpretable way. In order for logic models to provide a framework to support research and evaluation studies, they must contain elements that summarize the assumptions of how the intervention works. These elements include:

- The outcomes or the change that the intervention is trying to bring about
- Indicators of implementation that show what was meant to be delivered
- Mechanisms that show how what was being delivered as part of the intervention leads to a change in the outcome
- Characteristics of the context in which the intervention takes place that are likely to influence its implementation or its effectiveness *(18–19)*.

To ensure that a logic model captures these elements, they should represent – at a minimum – intervention activities or inputs, outputs, the intervention outcomes (which may be ordered chronologically), and the relationships between these. These elements are defined in Table 4.10.1, along with other elements that frequently occur in logic models, some of which may be particularly important for Health EDRM interventions.

**Table 4.10.1 Definitions of frequently occurring elements of logic models used in intervention research *(6, 13, 20–21)***

| Elements of logic models used in intervention research | Definition |
|---|---|
| **Distal or long-term outcomes** | Long-term outcomes are those theorized to occur following the initiation of an intervention and reflect broad concepts which are often analogous with the ultimate aims of the intervention. |
| **Intermediate outcomes** | Intermediate outcomes are theorized as being necessary pre-conditions of achieving distal or long-term outcomes and occur during follow-up after an intervention has ended. They may reflect behaviours that are among the ultimate aims of the intervention. |
| **Short-term or proximal outcomes** | Short-term outcomes are theorized to occur at the end of an intervention or soon after it has ended, as a direct result of the intervention. They are theorized to be necessary pre-conditions for triggering intermediate outcomes. |
| **Outputs** | Outputs are descriptive indicators of what the specific activities generate, and quantified and qualified indicators of the implementation of intervention activities. Unlike outcomes, outputs are under the direct control of those delivering the intervention. |
| **Intervention inputs: Activities or intervention components and processes** | Activities or components of the intervention that reflect what is being delivered. These are necessary to trigger the expected intervention processes and outputs. They may be represented as sequences of events in themselves, where one intervention component must take place before another component can begin. |
| **Intervention inputs: Resources** | Resources that are secured in order to deliver an intervention. They may be financial or may reflect the input or support of different stakeholders and might be identified through asset mapping processes (Chapter 3.1). |
| **Contextual factors or external factors** | These include population characteristics and the characteristics of the context or setting where the intervention takes place, which may moderate the way in which the intervention is expected to ‘work’. For disaster and emergency interventions, these may reflect pre-existing conditions or new factors that have emerged as a result of an event (for example, the emergence of violence or spread of a communicable disease such as cholera). |
| **Connecting arrows** | These form chains, linking intervention inputs with outputs and outcomes. Connecting arrows signal the direction in which the sequence of events take place and can be used to represent more complex relationships |
| **Additions for disaster or emergency interventions *(6)*: Goals** | These are broad statements about the long-term expectations of what should happen as a result of the intervention (see Salabarría-Peña, Apt and Walsh (*22)* for a further example). |
| **Additions for disaster or emergency interventions *(6)*: Objectives** | Statements describing the changes to be achieved, and the way in which change will occur (linked to the broader goal, with multiple objectives supporting the goal). |
| **Additions for disaster or emergency interventions *(6)*: Impacts** | Impacts reflect the way in which the intervention is theorized to meet its overall goal. As Birnbaum and colleagues *(6)* explain, impacts are the ‘so-what’ of the intervention. They represent the ‘high-level’ systemic change achieved at a community or population level (in practice, there may also be overlap with long-term outcomes). |

## 4.10.7 Constructing a logic model de novo

This section will briefly discuss the steps involved in developing a logic model de novo. There are several comprehensive resources to support this process *(4, 6, 13, 16, 20, 23)*, some of which include templates to guide researchers and policymakers *(24)*, including one specifically developed for disaster-related interventions *(6)*.

A first step in developing a logic model is to search for existing logic models for the intervention of interest *(13)*. However, despite nearly 60 years of the use of logic models by evaluators *(4)*, existing examples can be difficult to locate. Furthermore, any existing logic model will need to be adapted to reflect different contexts or priorities. Nevertheless, reviewing existing models is a useful preliminary exercise in starting to theorize the outcomes of interest and how they should be sequenced, and in identifying some key intervention processes linking inputs with outputs and outcomes *(25)*.

## 4.10.8 Steps in creating a logic model

**1. Involve stakeholders.**
Before developing a logic model, a key step is to secure the involvement of a range of stakeholders, in order to strengthen the salience of the model and its value in subsequent research activities *(8, 10)*. Different stakeholders (such as evaluators, policy-makers, community leaders) tend to hold different views and understandings, which are useful to incorporate when dealing with the uncertainty and complexity in humanitarian crises. Among other benefits, the involvement of a diverse range of stakeholders can:

- Create a useful challenge to the assumptions made in deciding how an intervention changes outcomes.
- Provide an opportunity to develop a consensus as to which outcomes measure the effectiveness of the intervention, and which outputs signal whether the intervention was successfully implemented.
- Ensure that diverse perspectives are represented.
- Help to identify how contextual factors extraneous to the intervention may facilitate or hinder the delivery of the intervention.
- Enhance the usefulness of the evidence produced for different practitioners and policy-makers.

**2. Identify the purpose or goal of the intervention.**
The overarching research question (Chapter 3.5), purpose or goal of the intervention should be identified and the major assumptions should be outlined. This may include key changes that have taken place in disaster or emergency settings, and theorizing about how these external factors will influence the goal of the intervention.

**3. Begin depicting the chain of events, starting with the distal outcomes.**
It is customary for the development of a logic model to begin by identifying and representing (usually in boxes) the distal or long-term outcomes that are expected to result from implementation of the intervention.

**4. Specify intermediate and proximal outcomes.**
The next step involves working backwards to identify or hypothesize the necessary preconditions (intermediate and proximal or short-term outcomes) that are needed to reach these distal outcomes. For example, in Figure 4.10.1, it was hypothesized that reducing the levels of MAM (long-term outcome) required reduction in levels of diarrhoea (intermediate outcome).

**5. Continue to develop outcome chains.**
The steps needed to reach longer-term outcomes may involve a number of pre-conditions (changes in outcomes) that are needed. Several “links”, represented as boxes or other shapes, could be added to the outcome chain.

**6. Add intervention outputs.**
After identifying outcomes, outputs are identified and represented within the model. Outputs are descriptive indicators of what the specific intervention activities generate, and represent necessary pre-conditions to reach outcomes, but are not necessarily goals in themselves (see Table 4.10.1).

**7. Develop intervention inputs/activities.**
Continuing to work backwards from the outcomes and outputs, chains of intervention inputs are specified. Areas of ambiguity about precisely how intervention activities are sequenced (that is, a ‘black box’ of intervention inputs) may be represented in the logic model as a single box, with the research or evaluation study building understanding of how the intervention is implemented.

**8. Complete initial model.**
An initial logic model will consist of input chains, comprising an intervention’s components and resources and how these are sequentially implemented, outputs, and outcome chains.

**9. Consider the nature of mechanisms.**
Mechanisms, or pathways of action, describe the nature of the action occurring between intervention inputs and outputs and outcomes. Not all relationships depicted within a logic model are simple linear (cause-effect) relationships, and more complex relationships may need to be included to better represent the likely mechanisms and to help guide data collection or analysis. An example is presented below and further examples are available elsewhere *(26–28)*.

**10. Consider the role of context, settings and stakeholders.**
Additional external or contextual factors, including the characteristics of populations, communities and other stakeholders involved in interventions, should be theorized and represented. These characteristics may be necessary for the intervention to ‘work’ (that is to say, without them the intervention cannot be implemented) or may moderate its effectiveness and amplify or dampen its success. In some cases, it may be easier to develop separate causal chains, or even separate models if an intervention is theorized to work very differently across diverse settings, populations or stakeholders.

**11. Continue to iterate**
It is expected that several iterations of the logic model will be developed before a preferred model is produced, with iterations representing an improvement in clarity, the conceptual soundness of the logic model, and more logical sequencing and organization of its elements. The logic model should be assessed for its consistency with existing research, broader theory, knowledge about the setting and logical plausibility *(4)*. Further iteration and development of the models may take place while the research or evaluation study is being conducted, on the basis of new knowledge generated (see also 'Update on the basis of new learning' below).

**12. Consider unintended consequences.**
Outcomes of interventions may deviate from their intended outcomes, and it is important to theorize about these unanticipated and adverse impacts. This process is described as modelling "dark logic" within interventions *(29)*.

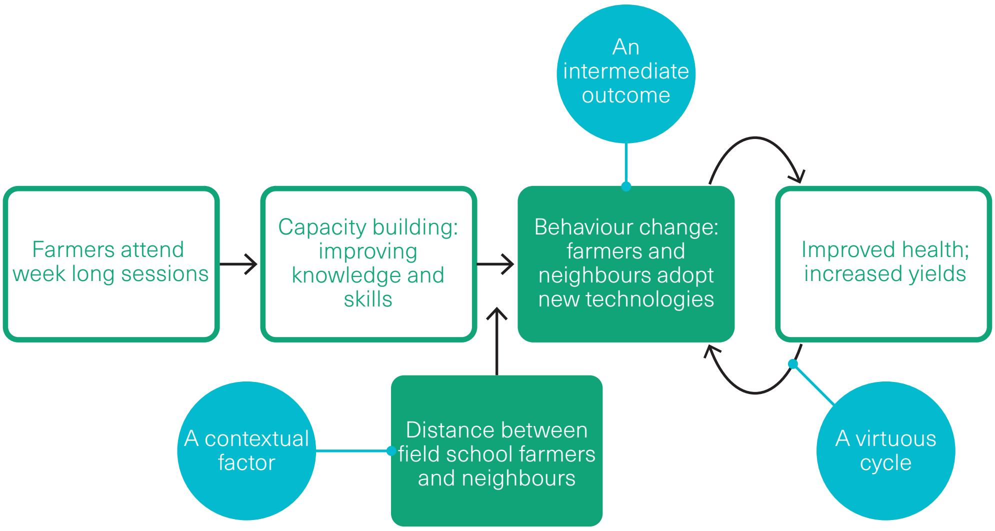
**13. Update on the basis of new learning.**
The research process is expected to generate new knowledge and evidence that may lead to changes in the logic model, or lead to an entirely new way of understanding how the intervention works. For examples of how logic models were updated based on new evidence see Harris et al *(25)* and Waddington and White *(30)*.

## 4.10.9 Representing more complex relationships in a logic model

To show how more complex relationships can be included in a logic model, we draw on the example of farmer field schools (FFS). FFS bring together groups of farmers in a community to empower them through learning about best practices in agriculture and, increasingly, about prevention, preparedness and response to disasters. The approach uses participatory models of education, including field-based experiments on neighbouring plots of land through a growing season, in order to examine the impact of best-practice techniques. FFS are believed to be useful in mitigating exposure to disasters and climate change *(31)*. The interventions have been considered as a means of reducing the risks of pesticide-related health emergencies *(30)* and as post-recovery measures for disaster-affected farmers *(32)*.

A systematic review of the effectiveness of FSS on outcomes including health was supported using a logic model *(30)*. A simplified and adapted version of that logic model is shown in Figure 4.10.2. The pathway outlines the steps between attending a FFS and improved health and yields, with three features of interest highlighted that can be represented in logic models. The first is the explicit mention of the intermediate outcome, which represents a factor that lies on the causal pathway between the intervention and distal outcomes. This demonstrates the functionality of a logic model being developed through theorizing a chain of pre-conditions needed to link the intervention with the outcome. The second feature of interest is the inclusion of hypothesized contextual factors (geographical and social distance between farmers) that are expected to moderate the extent to which new skills and behaviours developed among FFS participants will lead to improved knowledge and behavioural change among neighbouring farmers as well. Here, this contextual factor may amplify or dampen the relationship between exposure to the intervention and the outcomes. Such factors may interrupt or support the chain of events, but are not integral links in the causal chain. The third feature of interest is a 'virtuous circle', which is depicted in Figure 4.10.2 as a process whereby the adoption of new technologies among field school farmers and neighbour farmers leads to better health outcomes, by reducing farmers' exposure to pesticide in the environment, and better yields, via community-wide adoption of improved practices. This suggests that the impacts of the intervention could strengthen over time, and as the benefits of new technologies become apparent, this stimulates further adoption of new technologies. Virtuous cycles are activated when initial changes in the outcome create the opportunities for further positive self-reinforcing changes. Negative changes can be represented as 'vicious cycles'. Virtuous and vicious cycles are two of several more complex relationships that can be depicted in a logic model *(4, 26–28)*.

**Figure 4.10.2 Logic model adapted from a systematic review of the effectiveness of farmer field schools *(30)***



## 4.10.10 Logic model variants

As tools in research and evaluation studies, logic models offer flexibility and a spectrum of forms and uses are available in the literature. Some different variants of logic models are outlined below, drawing in part on work by Rehfuess et al *(21)*. These variants arise from differences in the priorities of the logic model at different stages of the research or evaluation study, or its scope.

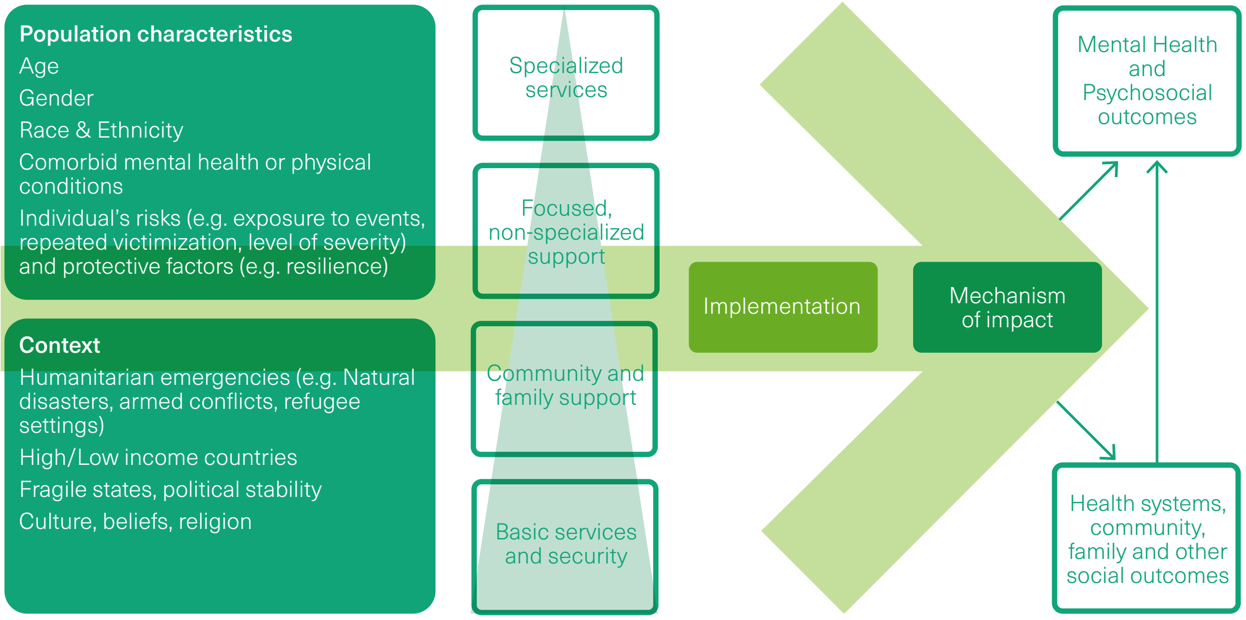
**Variant 1: Static, staged and iterative logic models**
A static logic model is one that is specified before the research or evaluation study, and remains in place without iteration throughout the study (although there may be an assessment at the end of the study as to how well the theory explained the evidence). A staged logic model is one where the theory is adapted or changed on the basis of interim findings or new knowledge, at planned stages of the research or evaluation study. Iterative logic models are those that are adapted at any point in the

research or evaluation study to reflect findings or new knowledge. This latter approach is more organic and responsive to new insights that may emerge, new questions that may arise, and any change in the priorities of the intervention *(25)*. A logic model should be assessed, and updated as appropriate, based on the findings of the research or evaluation study, with both the original and updated versions made available.

**Variant 2: System-based and process-based logic models**
A second distinction is between system-based logic models that aim to theorize aspects of complexity around the relationship between an intervention and the broader context and how these interact, and process-based logic models that focus more theorizing aspects of complexity between the processes occurring as part of an intervention and its multiple outcomes. Clearly there is some overlap between these types of model, and a single research or evaluation study may draw on both *(21)*. Process-based logic models tend to represent input and output chains in greater detail, reflecting a priority around understanding temporal sequences of intervention processes. Meanwhile, a system-based logic model depicts the system as 'the interaction between the participants, the intervention, and the context [in which it] takes place' *(21, p.15)*.

A system-based logic model may be particularly useful in accounting for the myriad ways in which different interconnecting components of health systems are impacted by health emergencies and disasters, and theorizing how interventions can restore these systems and 'build back better' to improve health. An example of a system-based logic model is reproduced from the paper by Bangpan, Chiumento, Dickson, and Felix *(33)*, which highlights in a simplified way the types of population characteristics, contextual and implementation factors and the combinations of these factors which may influence the effectiveness of mental health and psychosocial support interventions on people affected by humanitarian emergencies. Interventions in Health EDRM are often complex and sensitive to the context in which they are undertaken. This means that an intervention that is effective in one type of setting may be ineffective (or even harmful) in another population or setting, without modification *(34)*. A system-based logic model provides a starting point for theorizing whether there are aspects of the context (setting and existing health infrastructure) or population that are likely to facilitate or hinder the implementation and effectiveness of an intervention (Figure 4.10.3).

Figure 4.10.3 Components to consider in a system-based logic model *(33)*



### Terminology used when theorizing how interventions work

Although we outline the use of logic models, there are a number of different, overlapping, terms for tools that have been used to conceptualize how interventions work. Table 4.10.2 provides definitions for some of the alternative terminology in use, although in practice there are several overlaps between these concepts.

### Table 4.10.2 Definitions of frequently occurring terms around the use of programme theory

| Type of (Programme) Theory | Definition |
|---|---|
| **Programme theory** | A hypothesis explaining how an intervention is expected to lead to a change in the outcome. Graphical representations of programme theory can be developed into logic models or theories of change. |
| **Logic model** | A graphical representation of intervention processes, and outcomes linked by arrows indicating the direction of effect, which are developed into chains of cause-and-effect relationships. |
| **Theory of change** | Theories of change are used to represent complex interventions. Although there is overlap, unlike logic models, theories of change are more explanatory as they require all of the underlying assumptions of how and why different components, activities and outputs lead to a change in outcomes to be specified at the outset, as well as an indication of the context and the stakeholders affected. There can be multiple causal chains for different stakeholders. While there are differences between logic models and theories of change *(35)*, these differences are fuzzy and in practice the terminology is often used interchangeably. |
| **Logical framework** | The term logical framework or logframe is used to describe an array of different approaches. In some cases, the term is conflated with logic models. However, there are examples of logframes that are used more as project management tools that track how outputs, outcomes and impact are achieved according to different activities *(36)*. While useful as a project management tool, logframes are likely to be less useful as a tool for theorizing how interventions work, and particularly as a tool for theorizing aspects of complexity in interventions *(37)*. |
| **Middle-range theory** | Middle-range theories connect high-level sociological theories with empirical knowledge. In the context of interventions, middle-range theories include general principles about the ways in which interventions will 'work' across a range of situations (drawn from high-level theory), but also include some granular detail around intervention causal chains that can inform specific decisions about an intervention. Nevertheless, they are usually more generalized than programme theory, although there are several commonalities between middle-range theory and programme theory more generally *(38)*. There are few specific examples in the development literature of middle-range theories *(39)*. |
| **Conceptual framework** | Conceptual frameworks outline the main elements of the intervention and how it is meant to work, and may include a description of the context in which an intervention is expected to take place. A conceptual framework is not necessarily a graphical outline and the nature of the relationships between different components may not be explicitly articulated. |

### 4.10.11 Using logic models in evaluation and research

Logic models can be useful, practical aids for conducting a variety of research and evaluation studies, in several ways:

- As an engagement tool with stakeholders in the design of research and evaluation studies, ensuring that a diverse set of views are represented from the outset.
- Helping to design specific research and evaluation questions that can be used to guide studies and, similarly, in helping to identify the types of research approaches and methods that are suitable for answering questions that emerge from the logic model.
- Helping to decide what information needs to be collected about intervention inputs and activities, the characteristics of the contexts, and outputs and outcomes.
- Helping to design plans of how the research or evaluation data will be processed and for interpreting the findings.
- Communicating the results of the study through updating or redrawing of logic models on the basis of new knowledge.

Using a logic model provides a framework for understanding how an intervention channels an effect between the inputs and outcomes (40–41). Logic models are useful in unpacking the intervention ‘black box’ to aid understanding of the processes by which interventions can generate impact *(42).* This approach to producing evidence can help to move “beyond ‘business as usual’, generic programme designs through [developing] a greater awareness of the context”, with the logic model being a useful tool “to test the assumptions, demonstrate impact and learn from [interventions]” (*43,* p11).

### 4.10.12 Conclusions

There is increasing concern around improving the availability and use of evidence for Health EDRM *(44–45)*. At the core of good quality evidence is the use of theory to increase the robustness of the findings, the applicability and validity of any recommendations and enhance the generalizability (external validity) of the findings to other settings.

Using a logic model to theorize how an intervention works and how it interacts with context, and designing a research or evaluation study to test this theory, can be a useful basis for making decisions about which interventions to implement in which areas and for which types of emergency, as well as identifying whether interventions may need adaptation. Furthermore, for interventions that do not appear to be effective, evidence that is driven by theory is more likely to help distinguish between failures in intervention design and failures in intervention implementation (potentially due to context). Logic models represent a practical and applied approach for developing a theory of how interventions work which can be updated to incorporate new learning obtained through research and evaluation.

## 4.10.13 Key messages

- **Logic models provide a useful basis for thinking conceptually about how an intervention should 'work' to change outcomes. They are a graphical representation of the stages linking intervention inputs and outputs, outcomes and impacts.**
- **Logic models can be used to reflect assumptions about contexts and to illustrate more complex relationships.**
- **There are a number of steps to follow when developing a logic model, but perhaps one of the most important elements of good practice is that logic models should be developed with the input of stakeholders to challenge some of the (potentially erroneous) assumptions made by the research team.**

## 4.10.14 Further reading

**Resources that include logic model templates**

Birnbaum ML, Daily EK, O'Rourke AP, Kushner J. Research and evaluations of the health aspects of disasters, part VI: interventional research and the Disaster Logic Model. Prehospital and Disaster Medicine. 2016: 31(2): 181-94.

Rohwer A, Booth A, Pfadenhauer L, Brereton L, Gerhardus A, Mozygemba K, et al. Guidance on the use of logic models in health technology assessments of complex interventions. 2016 https://www.integrate-hta.eu/wp-content/uploads/2016/02/Guidance-on-the-use-of-logic-models-in-health-technology-assessments-of-complex-interventions.pdf (accessed 6 February 2020).

**Resources on how to develop a logic model afresh**

Kneale D, Thomas J, Harris K. Developing and Optimising the Use of Logic Models in Systematic Reviews: Exploring Practice and Good Practice in the Use of Programme Theory in Reviews. PLoS ONE. 2015: 10(11): e0142187.

**Resource on using logic models in research on complex interventions**

Kneale D, Thomas J, Bangpan M, Shemilt I, Waddington H, Gough D. Causal chain analysis in systematic reviews of international development interventions. CEDIL Inaugral Papers. Centre of Excellence for Development Impact and Learning, London. 2018. https://cedilprogramme.org/wp-content/uploads/2017/12/Inception-Paper-No-4.pdf (accessed 6 February 2020).

**Applied examples**

Bangpan M, Chiumento A, Dickson K, Felix L. The impact of mental health and psychosocial support interventions on people affected by humanitarian emergencies: a systematic review. In Humanitarian Evidence Programme. Oxfam GB, Oxford. 2017: https://policy-practice.oxfam.org.uk/publications/the-impact-of-mental-health-and-psychosocial-support-interventions-on-people-af-620214 (accessed 6 February 2020).

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4.11

# Researching communication and communicating research in Health EDRM

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## 4.11.1 Learning objectives

To understand the key factors to consider in evaluating and researching emergency risk communication programmes, including:

1. Specific objectives of communication before during and after disasters.
2. Particular challenges and opportunities in Health EDRM communication research.
3. Techniques used in measuring behavioural change inspired by communication programmes.
4. Key principles of quality communication – all of which require further research.

## 4.11.2 Introduction

At the third session of the United Nations International Strategy for Disaster Reduction (UNISDR) Global Platform in 2011, UN Secretary General Ban Ki Moon noted that success is measured by what does not occur — the school that did not collapse; the building that did not fall; the village that was not destroyed *(1)*. However, the data that are routinely available in Health EDRM research – usually from governments – tend to measure failure: death, destruction and economic loss. This presents a particularly difficult challenge for researchers of communication in disaster risk.

Although it may be reasonably straightforward for an engineer to attribute the survival of buildings to earthquake resilience strengthening, it is much more difficult to attribute human survival in an earthquake to understanding of (and giving effect to) the ‘Drop, Cover and Hold’ message, for example *(2)*. Public health practitioners are familiar with this conundrum.

They know that measuring interventional practice is easy, but that measuring the success of a preventive programme is always difficult, particularly where human behaviour is involved — and even more so in the case of hazards that occur infrequently. Success is measured by the absence of poor outcomes, but only when a hazard was manifest and risk was minimized. Measuring the absence of an outcome is challenging, particularly when the risk minimization is in the form of a behavioural change made as a consequence of a communication programme. For example, it may be impossible to determine how many cases of enteric disease were prevented by people following advice to wash their hands properly, how many cases of electrocution were prevented by people heeding the message to avoid downed powerlines during a storm, or how many lives were saved by people heading to higher ground on receipt of a tsunami warning.

Communication is one of five key elements of a resilient community, with the others being risk awareness, adaptability, learning and social capital *(3)*. Not only is communication within a community part of resilience in itself, but high-quality communication programmes can also be used to develop the other key aspects of resilience. Communication programmes that identify hazards, quantify risks and convey how to manage them, ideally resulting in population wide-behavioural change, are an essential component of Health EDRM.

Programmes that support communication among experts and general populations can deepen people's understanding of hazards, quantify risks, give guidance on how to manage them, prompt discussions about what can be done at different levels of society and motivate action. They can identify secondary complications of a disaster and ameliorate the psychosocial sequelae of a disaster for months or years afterwards.

WHO has produced a manual titled 'Communicating risk in public health emergencies', which is a guide designed to assist countries in building capacity for risk communication and how risk communication should be carried out before, during and after an emergency *(4)*. However, despite an expert guidelines group and rigorous guideline development methods, including scrutiny of the evidence base for best practice risk communication, the quality of evidence underpinning even the strongest recommendations, using the GRADE (Grading of Recommendations, Assessment, Development and Evaluations) system, was assessed as no better than moderate *(5–6)*. This shows that there is some uncertainty for practitioners of risk communication, but provides opportunities for researchers of risk communication to fill these important knowledge gaps.

Entertainment produces emotional changes, such as laughter, fear and excitement. Art can be entertaining, but goes one step further – with a key requirement of good art being that it makes you think. The art of communication lies in going further still. It requires not only getting people to think, but also inspiring them to change their behaviour. Like art or entertainment, there is a subjective component in the design and the appreciation of a communication campaign. However, communication can also be measured objectively. For example, an objective measure of the success of a communication programme may be whether the target audience have changed their behaviour and whether this behavioural change mitigated the adverse outcomes of an emergency.

There are earlier, intermediary steps to behavioural change. These include whether the communication imparts a greater understanding of the risks of disasters which a population may face and whether the understanding of these risks leads to an improvement in the knowledge required for mitigating them. It is also important to know what beliefs, perceptions, or social norms have shifted, enabling people to translate this knowledge into a change in behaviour, such as improved disaster preparedness kits, actions to build social capital or prompt appropriate responses to early warning systems.

### 4.11.3 Challenges in doing communication research in disasters

Although these outcome measures may appear to be relatively straightforward to measure, communication research in disasters is difficult for three reasons. First, disasters do not readily lend themselves to interventional studies. Even if a specific intervention can be applied to one group of people while keeping a similar group as a control before, during or after a disaster (which is often logistically impossible), it may be difficult to randomize some to receive a communication programme and some not to receive it *(7)* (see Chapters 4.1 and 4.3). Opportunities for randomization may present themselves through social media (messaging some people but not others, for example) but such randomization in the wake of a disaster would bring ethical challenges. Because the ethical and logistical difficulties of randomization may be insurmountable following a natural disaster, many evaluations of communication programmes are consequently reliant on observational studies, vulnerable to selection biases that can be at best only mitigated, but not entirely remedied, by careful interpretation.

Second, it is impossible to adjust for all the extraneous factors which may impinge upon a particular behavioural change targeted by a communication programme. For example, language skills may be an easily identifiable confounder of a communication programme, affecting both accessibility to a programme and understanding of a programme. Even within a group which uses the same language, subgroups may have a more proficient grasp of both passive (understanding) and active (persuasiveness) use of the language, which may confound results of a communication programme. Thus, the internal validity of a study to assess a communication programme may be compromised.

Third, when the wider social context of a community is considered, including economic and social factors such as employment or education, demographic make-up, ethics, laws and religions, it becomes very difficult to ensure the external validity of a specific communication programme. At best, principles can be learnt, but communication programmes themselves have to be tailored for and developed with the communities they are meant for. There is no such thing as ‘off the shelf’ communication.

## 4.11.4 Techniques to use in emergency risk communication (ERC) research

Notwithstanding these challenges, there are techniques that should be employed in ERC research that can provide some insights into how successfully a communication programme has promoted positive behavioural change with respect to Health EDRM. Only with a thorough, planned evaluation – covering formative process, impact and outcomes – of every ERC project, can techniques be refined and benefits demonstrated.

Effective ERC promotes emergency risk literacy, which is analogous to health literacy, as described by Nutbeam*(8)*. Emergency risk literacy represents the cognitive and social skills that determine the motivation and ability to gain access to, understand and use information in ways that promote and maintain good health through the management and mitigation of emergency risk. However, promoting emergency risk literacy in individuals alone (a behavioural change approach) is unlikely to produce the most beneficial results.

The behavioural change approach of health promotion is based on the belief that providing people with information will change their beliefs, attitudes and behaviours *(9)*. Although a popular model, the provision of information on its own is rarely enough to change behaviour because it ignores the factors in the social environment that affect health, including social, economic, cultural and political factors *(10)*. Similarly, without taking into consideration the broader determinants of health in ERC, risk management is likely to be limited. The development of individual responsibility alone is rarely sufficient to effect sustainable behavioural change.

An extension of the behavioural change model is the self-empowerment approach, in which people are encouraged to engage in critical thinking and critical action at an individual level. This model aims to develop 'risk management skills', including decision-making and problem-solving skills, so that the individual is willing and able to maintain control of their life during an emergency. While this model can be successful for some individuals, it is unlikely to be successful across a whole population because it does not address social norms *(11)*.

## 4.11.5 Taking into account the determinants of health

In order for ERC to be sustainably successful at a population level, the determinants of health must be taken into consideration. The social determinants of health are the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life *(12)*. Determinants of health include education, housing, employment and the environment. They have a far greater effect on health outcomes that the provision of health services alone. Addressing the determinants of health also has a far more profound effect on the ability of a community to manage emergency risk than simply providing the information alone. At the most fundamental level, the three ultimate determinants of disaster risk are poverty, inequity and planetary health (including climate change). These three determinants are also the key modulators of emergency risk management, and so must be addressed by ERC. These three fundamental issues underpin the great UN initiatives of 2015 – the Sustainable Development Goals, the Paris Climate Change Agreement and the Sendai Framework (Chapter 1.2) *(13)*.

Addressing the determinants of health and disaster risk requires a collective action model – a socio-ecological approach that takes into account the interrelationship between the individual and the environment. Although individual empowerment is necessary, it is not sufficient to generate change at a population level. The collective action model generates population-level change by encompassing ideas of community empowerment and requiring people to individually, but also collectively, acquire the knowledge, understanding, skills, and commitment to improve the societal structures that have such a powerful influence on a community's ability to manage disaster risk *(14)*. It engages people in critical thinking in order to improve their understanding of the factors affecting individual and community well-being. It also engages groups of people in critical action that can contribute to positive change at a collective level.

## 4.11.6 Components of communicating risk effectively for emergencies

Whichever model is used, there are three essential components to communicating risk effectively for emergencies *(4)*: building trust, integrating communication into prevention, preparedness, response and recovery and specific techniques (including developing a compelling message with the target community, identifying the appropriate balance of media for communicating the message and evaluating the programme).

**1. Building trust**
Techniques used in both the development and the evaluation and research of communications strategy may be similar, and involve a mix of qualitative and quantitative methods (Chapter 4.13). Audience reach data is often already available from print and broadcast media, which may indicate which media are most trusted for, and used to garner, information. Generally, familiarity engenders trust in individuals, so elders are often more trusted than younger people, but this may need to be confirmed at a local level through surveys, focus groups and interviews.

**2. An integrated approach**
Communication needs to be integrated into every level of risk management. Bringing media and communication experts into the planning process is more likely to produce messaging which is acted on than simply providing information to the media. Moreover, commercial media have skills in measuring content and effectiveness of messaging beyond that usually found in health organizations. Experts in communication can provide valuable advice when considering the choice and balance of the multiple means by which the message is conveyed. This will also require careful consultation with 'target' communities and their agencies. There is also useful information to be garnered from wider consultation with other agencies (such as government, nongovernmental and private business), which can inform the communication process. For example, some agencies will have information on which people in a community are key

influencers and certain agencies may have specific skills in messaging. The planning process should cover all aspects of emergency risk management, starting with identifying and mitigating risk. During an emergency response, communication will usually focus on immediate survival issues ('drop, cover and hold' in an earthquake; 'seek higher ground in a tsunami', for example). Once the immediate threat is over, there will be a much longer period of recovery involving primary care, maternal and child health and subsequently an even longer period of psychosocial recovery that will involve employment, housing, education and the agencies responsible for the wider determinants of health.

### 3. Specific techniques

The seven Cs of a good communication were originally described more than sixty years ago in the context of 'public relations' *(15),* but these principles have been adapted for many areas of communication, including humanitarian relief *(16)*:

- Correct – evidence based
- Concise – pithy
- Clear – it says what you mean
- Courteous – cultural values are important
- Complete – as comprehensive as possible
- Considered – with the target community and the agencies which serve them
- Concrete – be specific, not vague.

Despite the apparent objectivity of this schema, developing a good message is more art than science, which is why the involvement of a good communications team in message development is important. Good advertising slogans are often attributed with improving the sales of a product – sales of Nike running shoes went up tenfold in ten years after 'Just Do It' was introduced, for example *(17)* – but slogans to change behaviour during a disaster are more difficult to develop and more difficult to evaluate. 'If it's brown, flush it down; if it's yellow let it mellow' was a slogan used to minimize toilet usage and protect the fragile sewerage system after the Christchurch earthquakes *(18)*. It ticked most of the seven Cs, but there has been no formal evaluation of the message's success.

Deciding which media to use can be difficult. Increasingly, social media is used to convey messages *(19)*, but conventional television, radio and print media still have a place. For example, Katy Perry, Barack Obama and Justin Bieber each have more than 100 million followers on their Twitter accounts, but more than 3.5 billion people watched the FIFA world cup final on television in 2018. In some cases, a 'soapbox' presentation to an audience may be the best way to deliver a message, especially if power is out and buildings are destroyed. Once again, consultation with the target audience is important, using a collective action model of health promotion. Local knowledge can help decide which media mix will gain the greatest attention.

### 4.11.7 Research and Evaluation

The evaluation and research of any communication campaign requires a mixture of quantitative and qualitative methods (Chapter 4.13). Data gathering tools include focus groups, surveys, interviews, case studies, social media and/or website monitoring ('hits'). A series of measurements – formative (baseline), process, impact and outcome measures – will need to be budgeted for, in order that changes in awareness, knowledge and ultimately behaviour can be tracked over time. Questions about specific communication programmes can be added to routine surveys or market research, as well as specific surveys tailored to the programme be carried out. Well-funded, well-designed and well-implemented surveys should follow a communication strategy over time (before, during and after), and be able to compare different specific subgroups targeted by the strategy.

Such surveys are able to concentrate on positive outcomes of communication programmes, where routinely collected data tends to focus on negative outcomes of disasters. Questions should follow the pattern:

- Are you aware of the programme?
- Did the programme convey knowledge to you?
- Did you change your behaviour as a result of this knowledge?

Behavioural changes can sometimes be corroborated by objective measures. WHO has identified gaps in communication research and evaluation which, although they highlight deficiencies in current knowledge, also identify where there are research opportunities in the future. These gaps/opportunities include a lack of longitudinal studies and of studies of behavioural change (outcomes).

The gaps and research opportunities are particularly marked in low-income countries and among low income or vulnerable groups.

## 4.11.8 Case studies

The following four case studies highlight examples of communication research relevant to Health EDRM.

### Case Study 4.11.1
### The 'All Right?' Campaign, Canterbury, New Zealand 2012

The 'All Right?' campaign is a population-based, multi-media health promotion aimed at improving psychosocial well-being following the 2010-2011 Canterbury earthquakes. It was formatively evaluated and has been continuously evaluated through a series of iterations over several years *(20).* Methods of quantitative and qualitative evaluation include semi-structured interviews for process evaluation, survey questions developed with a market research company aimed at 400 randomly selected Christchurch residents, and specific tailored questions addended to the Canterbury Well-being survey – which is a survey of more than 2000 people carried out initially every two years, then annually to monitor Cantabrians' well-being in the wake of the earthquake sequence *(21).* In May 2018, half of Cantabrians (population 400 000) were aware of the 'All Right' campaign and of those who were aware of it, nearly 90% thought the messages were useful. More than 70% felt that the messages were useful for them personally and 42% claimed to have done at least one of the simple activities advocated by the campaign including, but not limited to, the Five Ways to Well-Being – Communicate, Learn, Be Active, Take Notice and Give (22).

The 'All Right' campaign in conjunction with the Canterbury Well Being survey, is an example of a thoroughly planned and researched communication programme. Inevitably, well-being is often measured subjectively and may require corroboration with more objective measures.

### Case Study 4.11.2
### ’Staying Alive’, Health Professional led Urban Radio, Ghana 2015

A formative evaluation identified a gap in information, education and communication about policies and practices in healthcare delivery, healthcare financing, training, ethics, research and environmental issues in Ghana (23). In June 2015, medical practitioners collaborated with a private, local, English-speaking radio station to produce and host a weekly health show whose content was aimed at discussing health from the viewpoint of practitioners, clients, policy makers, administrators and financiers in a simplified language for the general public, including healthcare trainees.

Since July 2015, the show, called ‘Staying Alive’, has aired weekly with audience analysis demonstrating its appeal to a wide range of active listeners. ‘Staying Alive’ remains one of the only shows in Ghana with a holistic approach to health hosted by health professionals. The evaluation of the impact of the show was crudely measured by the number of messages received and the number of telephone calls during the call-in segment. The integration of Facebook live expanded the reach of the show and Facebook analytics were useful in determining how many people watch the live show. Listener surveys by a commercial media measurement company (GeoPoll) was able determine a high number of people listening to the ‘Staying Alive’ compared with other English-language programmes but could not measure the impact of the message and its eventual impact on health.

This shows that where resources are stretched, pre-planning and appropriately detailed research and evaluation are difficult; but that international collaboration may help to address the gaps.

### Case Study 4.11.3
### ‘Amrai Pari’ reality TV programme, Bangladesh 2014

BBC Media Action is the BBC’s international development charity. It supports media and communication efforts that strengthen governance, improve people’s health, increase their resilience and improve emergency response. In Bangladesh, BBC Media Action broadcast a national TV reality show to build resilience alongside roadshows and work with the Bangladeshi Red Crescent to integrate new communication tools into their already established system of long-term, two-way conversations with communities about risk identification and resilience. The Amrai Pari (‘Together We Can Do It’) reality television programme helps build people’s resilience by empowering communities to work together to be prepared for extreme weather conditions. It started as a television programme, but also includes events teaching practical life-saving skills, educational performing arts shows involving music and drama, and festivals with up to 2000 attendees. The programme featured communities adopting low cost, replicable solutions to everyday problems caused by extreme weather and changing weather patterns.

The project reached 22.5 million Bangladeshis, with impact research showing 78% of viewers reporting better understanding of how to prepare for extreme weather – and, more importantly, 47% of viewers reporting they took action after watching the programme *(24)*.

This highlights how BBC Media Action produces communications programmes that are thoroughly formally evaluated and researched and based on tried and tested communication models. Like the ‘All Right’ campaign in Case Study 4.11.1, the evaluation relied in large part on subjective evaluation.

### Case Study 4.11.4
### The Pandemic Roadshow, New Zealand 2007

In conjunction with a local virologist, a dietician, a public health physician and an emergency planner, a children's science museum in New Zealand developed six portable exhibits designed to demonstrate the risks of influenza and how they could be mitigated and prepared for. The exhibits were based on the mnemonic CHIRP representing 'Cough etiquette', 'Hand Hygiene', 'Isolation', 'Reducing germs' and 'Preparation'. Cough etiquette showed how far people need to keep apart to prevent the spread of respiratory viruses. Hand hygiene used glow gel to demonstrate how easily germs can spread if hands are not washed properly. Isolation used a domino display to demonstrate how one infected person can lead to many more people succumbing, and how this is prevented by appropriate social distancing. Reducing germs showed how the influenza virus can be transmitted on surfaces which are not cleaned properly. Preparation challenged participants to find appropriate items for an emergency preparedness kit. The sixth display demonstrated a suitable healthy preserved food store for a family of four (and one pet) for a week. This exhibition was circulated among local government leaders, public libraries and schools for two years in conjunction with more conventional preparedness messaging delivered by video or print media.

In the region of New Zealand where the Pandemic Survival Roadshow was used, a random telephone survey demonstrated that the proportion of local population who were aware of the threat of pandemic influenza was almost twice that of the national average. In addition, people who had viewed the Pandemic Survival Roadshow were statistically significantly more likely to have an emergency preparedness kit. Such preparation served the population well during the 2009 H1N1 influenza pandemic and the all hazards approach had spin off benefits when the same population was affected by earthquakes in 2010 and 2011 *(25)*.

This case study shows how awareness following the Pandemic Survival Roadshow was objectively evaluated and compared to other areas across the country. The effectiveness of the programme, particularly with respect to the all hazards approach, was able to be tested (unfortunately) by the Canterbury earthquake sequence, which followed closely after the H1N1 2009 influenza pandemic.

## 4.11.9 Conclusions

Health EDRM research is inherently challenging, and nowhere more so than in the area of emergency risk communication. However, by integrating communication programmes into all aspects of the disaster cycle, developing the programmes using evidence-based techniques, using the appropriate balance of media for delivering the programmes and following recognized schema for evaluating such programmes, a valuable contribution can be made not only to disaster risk reduction in the communities served, but also to generating transferable knowledge to inform future emergency risk communication programmes in a diverse range of situations and societies.

## 4.11.10 Key messages

- **Emergency risk communication (ERC) is an essential part of emergency preparedness.**
- **The essential components of effective communication during emergencies are trust, integration and the seven “C”s of effective communication – correct, concise, clear, courteous, complete, considered, concrete.**
- **Research and evaluation of ERC can be difficult in the pressured environment of an emergency or disaster, but can be achieved with careful advance planning.**
- **In order to learn from and improve ERC, formal evaluation techniques should be applied to ERC, which requires forethought and funding.**

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# 4.12 Qualitative Research

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## 4.12.1 Learning objectives

To understand key factors to consider when developing a qualitative study for health emergency and disaster risk management (Health EDRM) research, including:

1. The epistemological foundations of qualitative research commonly used in disaster research.
2. Common qualitative research methodologies used extensively in disaster research.
3. Different methods used in qualitative data collection.
4. The power of participatory, performatory and arts-based research methods in disaster risk reduction (DRR).
5. Common issues and challenges for qualitative research in a disaster context.

## 4.12.2 Introduction

This chapter presents an overview of qualitative research methodologies that are commonly used in the study of disasters and relevant to Health EDRM. It highlights different types of qualitative methods and the challenges associated with each type, and explains how qualitative designs can be used to round out the evidence base and fill knowledge gaps. The chapter focuses on the epistemological foundations of the qualitative research methodologies commonly used in disaster research; information on other factors influencing qualitative research is available elsewhere (for example, see Chapter 3.4 and Philips *(1)* on ethical issues in disaster research, Emmel *(2)* on sampling, Saldaña *(3)* on data coding and Curtis and Curtis *(4)* on analysis).

Although disaster research has typically focused on quantitative methods – particularly modelling and survey designs *(5)* – qualitative methods have a long history of use within disaster research *(1)* and are able to provide different types of evidence. Despite this, qualitative approaches are increasingly marginalized in discussions of evidence-informed practice or DRR policy development, in comparison to the greater attention given to indicators, tools, measurements, computer simulations and technological solutions in discussions of evidence-informed practice or disaster risk reduction (DRR) policy development *(6–7)*. However, the unpredictability of disaster contexts, combined with the need to capture time-sensitive information, means that qualitative research is often more practicable than quantitative study designs *(1, 8)*.

## 4.12.3 What is qualitative research?

The approaches to qualitative research introduced in this chapter are primarily concerned with 'the exploration of lived experience and participant-defined meanings' *(9)*. This version of qualitative research looks at the world from a naturalistic and interpretive perspective, situating the researcher in the world they are exploring *(1, 10)*. Qualitative research includes primary and secondary data collection and analysis. Primary data is collected face-to-face by the researcher through asking people about their interpretations, understandings, and lived experiences of a particular topic or event. Secondary qualitative data collection involves an exploration of pre-existing sources of information such as websites, publications or media reports *(11)*. Depending on the type of research question, the data generated through qualitative research designs may include participant narratives and field notes from observations, as well as photos, videos or documents. As described by Denzin and Lincoln, qualitative research practices "turn the world into a series of representations, conversations, photographs, recordings, and memos to the self" *(10*, p.3). Qualitative research can help inform and guide evidence-based practice in public health *(12)* and DRR *(13)*.

Rather than focusing on numbers *(14)*, qualitative researchers focus on the qualities of the topic being explored. When a research question seeks to answer 'what?' or 'how?' *(1, 9)*, qualitative research is typically the best strategy *(15)*. Qualitative research contributes by exploring people's meanings, perspectives and experiences, studying how things and systems work, understanding context and unanticipated consequences, as well as discovering important patterns and themes across cases *(16)*. According to Creswell *(15)*, the strengths of qualitative research include:

- Reporting results in the voices of participants
- Placing research in its natural setting to include important contextual factors
- Smaller sample sizes allow greater depth of findings
- Emerging, exploratory and open-ended design allows flexibility in design for different populations
- Good design for marginalized populations
- A starting point when little is known about a topic
- Allowing multiple perspectives on a phenomenon

- Allowing study of sensitive topics
- Allowing for a complex understanding of a phenomenon using inductive and deductive reasoning.

### 4.12.4 Differences between qualitative and quantitative research

The dominant discourse around research has traditionally been focused on objective measurement, large representative samples and validity; these concepts are embedded in quantitative research designs *(17–18)*. Quantitative research describes social phenomena by using the breadth of data to facilitate broad and valid generalizations about populations *(15)*. In contrast, qualitative research aims to develop understanding of social phenomena through exploring, describing, troubling or explaining them. Qualitative research is based on an interpretivist (as opposed to a positivist) paradigm *(19–20)*. Qualitative approaches focus on in-depth analysis of data, the findings of which highlight the underpinning factors that explain the social world. Although qualitative designs can in some cases complement quantitative methods, as is it the case in mixed methods studies (Chapter 4.13), in general, qualitative methods generate different types of data, which enable researchers to answer different types of questions that quantitative designs are not suitable for *(20–21).*

Qualitative and quantitative forms of research correspond respectively to inductive and deductive approaches to inquiry. Inductive research, which is favoured in qualitative research, is a 'bottom-up' approach that involves reaching a conclusion based on observation and analysis of data gathered in the field. Inductive research builds theories based upon data collected in the process of doing research *(22)*. Deductive research, which is favoured in quantitative research, is a 'top-down' approach to theory and research that means finding a solution to a problem based upon evidence *(22)*. Deductive research tests theories which are developed through what is known in the existing literature and validated or troubled through the process of doing research *(4)*. It is common for researchers to use both inductive field-based theories and deductive literature-based theories in the analysis of qualitative research.

Table 4.12.1 summarizes common differences between qualitative and quantitative research methods. This list is adapted from and combines lists presented by Creswell *(15, p.15)* and Denzin and Lincoln *(10),* who have summarized the differences to help researchers decide which approach to use.

**Table 4.12.1 Common differences between qualitative and quantitative research (adapted from *(10)* and *(15)*)**

| | Qualitative Research | Quantitative Research |
|---|---|---|
| **Purpose** | Understand and explore behaviour, opinions, experiences from participants' perspectives | Describe social phenomena; Discover facts |
| **Design** | Emerging and flexible | Standard and fixed |
| **Paradigm** | Multiple interpretations of reality exist (subjective) | Reality is fixed (objective) |
| **Setting** | Naturalistic (contextual) | Controlled (empirical) |
| **Sample size** | Small | Large |
| **Data Collection** | Open-ended<br>Observation, interviews, focus groups, narratives, document analysis, artifacts | Closed-ended<br>Objective measurements<br>Questionnaires and surveys |
| **Data analysis** | Inductive<br>Themes, text, images | Deductive<br>Numerical comparisons and statistical inferences |
| **Biases** | Acknowledged and assumed to influence findings | Reduced or eliminated |
| **Standards for Quality** | Dependability, Credibility and Authenticity, Auditability, Transferability, Confirmability | Internal Validity, External Validity, Reliability, Objectivity |

## 4.12.5 Assumptions in qualitative research

A key point to remember is that qualitative research and quantitative research are based on different assumptions. Much of the debate about the differences between the two approaches concerns paradigms, which are sets of beliefs or worldviews *(23)*. In quantitative research, it is assumed that bias must be reduced and eliminated (Chapter 4.1). In qualitative research, bias is acknowledged and assumed to influence the interpretation of the findings. When reports of qualitative studies are peer reviewed, it is not uncommon for critiques from inexperienced reviewers to include the need to eliminate bias. However, bias is inherent in any research project and is part of the underlying assumption in qualitative designs *(17)*. It is important when reading reports of qualitative studies to understand this underlying assumption and focus on how rigour is managed in the study.

Methods for enhancing rigour in qualitative research are built into the study design in order to ensure interpretations are accurate representations of the data generated. Although researchers have identified as many as 60 ways to think about research *(22)*, this section focuses on five worldviews that frequently inform qualitative disaster research: social constructionism (*24)*, post-positivism, advocacy or participatory approaches, and pragmatism *(23)* as well as the importance of reflexivity in research *(25)*.

Post-positivism is based on the assumption that findings cannot be proven beyond doubt, but that confidence is improved through robust measures of reliability and validity. Researchers should remain neutral and reduce bias through attempting to both verify and falsify their hypotheses (*26)*. Post-positive approaches are suited to research that attempts to predict how people will act in a given situation.

Social constructionism recognizes that knowledge is not disinterested or apolitical, and that understandings and meanings are constructed and sustained through social interaction. Multiple realities co-exist, foreclosing the notion that there is one universal truth *(26)*. Social constructionism is particularly useful in the study of identity as well as of experience. In contrast, social constructivism has many similarities with social constructionism, but tends to focus on how individuals learn through social interaction within their peer group. As an example, research knowledge in this view is co-created by researcher and participant *(10)*. An example of the social constructivism approach may be found in the '7 Up' documentary series *(27)*.

The advocacy or participatory approach recognizes that lay people have their own knowledge systems and are able to act and solve local problems. Participatory research is community based, empowering and transformative *(28).* Participatory research is particularly useful when working with communities or marginalized groups.

Pragmatism is the belief that the meaning of actions and beliefs are found in their consequences. Actions are situational, depend on shared sets of beliefs, and linked to consequences that are subject to change based on new experiences. Pragmatism, for example, is implicated in the choice of research method as assumptions are made about the research outcomes that may result from each method. Pragmatic inquiry is particularly suited to research in the area of decision making as well as in relation to novel events *(21).*

In qualitative research, reflexivity involves 'understanding the role of self in the creation of knowledge' *(25*, p. 220) through attention to how the situated knowledge of the researcher impacts on their research (for example, their choice of research design, disciplinary background, beliefs, personal experiences and demographic characteristics) *(25, 29)*. It is therefore important to be transparent with the reader about the researcher's worldview because it will have practical implications for the study, including theoretical frameworks, methodologies, and methods *(23)*.

### 4.12.6 Subjects versus participants

In qualitative studies, people who contribute to the research by being interviewed or completing arts-based activities as part of data generation are referred to as participants or co-researchers, rather than subjects. This discourse is reflective of a paradigm where research is not done 'on' subjects, but 'with' people. In many participatory methods, there are strong relationships between the researchers and participants or community organizations. These relationships and projects can span many years, and there is joint ownership and direction of the projects. In a disaster context, this point is extremely important given the nature of projects where citizens and communities may be in vulnerable settings following a disaster. The term 'participants' conveys voluntary engagement in the research and reflects the relationships in partner-based projects.

## 4.12.7 Five common approaches to qualitative research

Reports of qualitative research should provide a detailed description of the approach, reference seminal authors and justify why the approach was chosen and how the approach informs the procedures of the study (for example, interview type, focus group, observation and so on *(30)*). Outlined below are five common research methodologies used in qualitative research, as described by Creswell *(30)* – narrative research, phenomenology, grounded theory, ethnography and the case study. Also included are a brief description of ethnomethodology and a case study that highlights its application in New Zealand, in order to illustrate the potential of this approach for disaster research.

### Narrative research

Narrative research explores people's experiences, as told in the form of stories from one or more individuals of interest *(30)*. Ideally, this leads to an exploration of an individual's life, their identity and how they situate themselves in the world. Storytelling, giving an account of events or actions, predominantly uses interviews and documents to collect the data, but can also rely on observation, use of pictures and group conversations as data collection methods. Several strategies for data analysis can be chosen, depending on the purpose of the research, including thematic analysis, structural analysis and dialogic/performance analysis. It is common for researchers to 're-story' or reconstruct a story told by a participant, so that the report presents the story chronologically, highlighting 'turning points', and important contextual information. With this restructuring, the researcher is often seen as a collaborator in the storytelling process and thus requires much reflexivity on the part of the researcher to reflect on their own assumptions and experiences and how that might affect the way they re-story the data. An additional challenge to this type of research is the amount of data collection that must occur to capture a full and clear picture of the context surrounding the story.

### Phenomenology

The purpose of phenomenology is to understand the universal 'essence' of the experience of a phenomenon *(30)*. This approach differs markedly from narrative research as phenomenology goes beyond the individual experience to describe the common meaning for several individuals. In this case, the unit of analysis is 3 to 25 individuals who have all experienced the same phenomenon (such as grief). Just as for narrative research, individual interviews are the most common method of data collection. However, documents, observation and art have also been used. The researcher's stance in phenomenology is to bracket themselves out of the study by reflecting on personal experiences with the phenomenon and setting those aside to focus on the experiences of their participants. Textual and structural analysis of the data summarizes what and how the phenomenon is experienced, ending with a descriptive report of the universal essence. Challenges to this approach include discussing philosophical assumptions of abstract concepts (such as grief), careful selection of participants so that they have all experienced the same phenomenon, and the difficulty that researchers often find in trying to bracket their personal experiences with the concept under study.

### Grounded Theory

The purpose of grounded theory is to generate a theory that is grounded in the data to explain a process (for example, the process of dying) *(30)*. Grounded theory uses theoretical sampling to collect data from 20 to 60 participants who have all experienced a process. As is the case with narrative research and phenomenology, one-on-one interviews are the most common method of data collection. The grounded theory researcher constantly compares data across interviews with their memos on the researcher's emerging ideas for a theory. The data analysis strategy used depends on the grounded theory approach a researcher chooses. Glaserian grounded theory uses active codes (see Charmaz *(31)* for more on this approach), while Straussian grounded theory uses open coding, axial coding and selective coding (see Corbin & Strauss *(32)*). It is important not to confuse literature on the two distinct approaches. Straussian grounded theory presents a more structured approach than the Glaserian methodology. In their final report, the researchers will produce a diagram, hypothesis or both to accompany the discussion of their results. A negative attribute of this approach is that it tends to be reductive.

### Ethnography

Ethnography describes the social behaviours of a culture-sharing group *(30)*. Here the researcher is tasked with both describing and interpreting topics such as group values, behaviours, beliefs and languages learned. In this case, the unit of analysis is an entire – or subset of a – large culture-sharing group. This approach requires extensive fieldwork using a variety of data collection methods, such as observation, interviews, symbols and artifacts. Most often, researchers are participant observers in which they become immersed in the day-to-day lives of the group they are researching, both observing and participating in the world around them. Data analysis in ethnography typically begins with an insider emic perspective of the data through verbatim quotes, which then gets moved into an etic scientific perspective to develop the overall interpretation of social behaviours of the group. There are several approaches to ethnography including, but not limited to autoethnography, critical ethnography, participatory action research and realist ethnography.

### Case study

The purpose of a case study is to develop an in-depth understanding of a single case, or multiple cases *(30)*. Cases can be one person, several people, a group, a programme, an activity, a setting and so on. It is important that the case be clearly defined within a bounded system. A distinct characteristic of the case study is the use of multiple sources of data or multiple forms of data collection methods in a single study to develop an in-depth understanding of the case. Data collection methods can include interviews, observations, documents and artifacts. Data analysis can be explanatory, exploratory, or descriptive using themes and cross-case themes. Approaches to a case study differ depending on whether the researcher wishes to look at the case itself (intrinsic), the wider purpose of the case (instrumental), or look at comparing cases (collective case). It can be difficult to successfully identify and bound a case, and to keep a case study focused, because the more cases are studied, the more the overall analysis will be diluted. For this reason, it is recommended to include no more than four or five cases in a multiple case study design. It is also important that, whatever decision is made, a rationale is provided for these choices.

### Ethnomethodology

Ethnomethodology has its origins in sociology and a focus upon disruption, which makes it a particularly useful research method in Health EDRM and disasters. This research methodology explores singular events, including how people interact and make sense of occurrences. Although similar to ethnography, ethnomethodology differs through its focus on the knowledge and methods employed by people in their everyday lives (for a discussion of differences between ethnomethodology and ethnography, see Pollner and Emerson *(33)*). Ethnomethodology considers the context of language and meaning through attention to the work of the streets. In an ethnomethodological approach, disruption enables consideration of the process through which the stable features of social organized environments are created and sustained *(34–35)*. Ethnomethodology may be used to look at the everyday micro processes of social interaction, as well as how people cope with and make sense of large scale events *(36)*.

As an example of paying attention to the work of the streets, people in Canterbury New Zealand used the term ‘munted’ to create a shared language around the 2010-2011 earthquakes, as the images in Figure 4.12.1 illustrate.

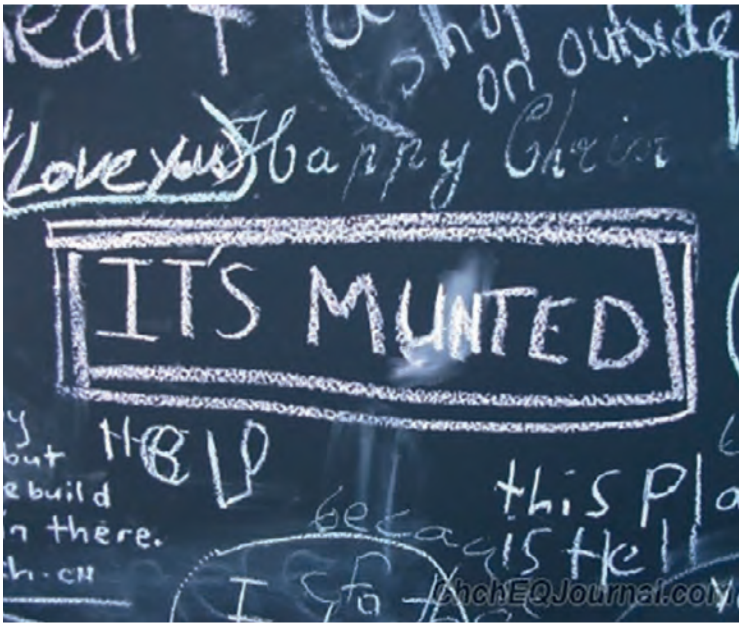
**Figure 4.12.1 The creation of a shared language in relation to the Canterbury Earthquakes**

munted

adj (1) used to describe severe levels of damage in Christchurch earthquake. (2) used to avoid offending others by saying f**ked in the context above...

Origin, Christchurch NZ
February 2011...

Source: Outside the Square Creative, https://www.outsidethesquare.net.nz/portfolio/munted/



Source: ChchEQJournal.com. Written on a community blackboard in which people shared their feelings, Christchurch, February 2011.

Use of the term ‘munted’ was also evident in the following sample narrative texts from qualitative studies conducted in Christchurch by Phibbs and Kenney, following the Canterbury earthquake sequence:

*I was getting text after text… don’t go down Fitzgerald Ave, no bridge. Dallington is munted, no access. St Albans is closed*
(NL, Female, 2012, Māori community research).

*P1: The house next door to us… that’s triple brick so it’s got no internal… timber framing,… it’s basically just cracked right through… P2: It’s munted*
(P1 Male, P2 Elderly Female 2012, disability and disaster research).

*We didn’t open the marae (Māori community centre) because we had no toilet facilities… so we weren’t able to operate, we had all our ablution block, piping, our plumbing that was all totally munted so it couldn’t happen for us*
(ML, Female, 2012, Māori community research).

The term ‘munted’, which before the earthquakes had referred to an intoxicated person or something that was broken, came to symbolize the way in which individuals were interpreting and expressing their experiences of the post-disaster city.

A fundamental premise of ethnomethodology is that social reality and social order are accomplished through the ongoing actions of individuals who ‘make meaning’ out of the practices of everyday life *(26, 33)*. Disasters, as disruptors of everyday life, lend themselves to ethnomethodological analysis because they bring into view the taken-for-granted ‘sense-making’ processes through which social life is experienced, ordered and sustained.

### 4.12.8 Community-based participatory research (CBPR)

This chapter highlights one type of participatory approach to research, which is not limited to but frequently employs qualitative methods – community-based participatory research (CBPR). Because many disaster studies focus on the community level, it is often desirable and necessary to adopt participatory designs. This type of research has different names: participatory action research, advocacy research, CBPR, or community-led research (CLR), which is more commonly conducted by Indigenous researchers in partnership with Indigenous communities (see also Chapter 5.4). However, the premise is the same, with a focus on creating social change with a community through collaborative partnerships and shared decision-making. Regardless of whether a study is being done before a disaster (for example, prevention, mitigation or preparedness) or during and after (response and recovery), there are important guidelines for working with communities. When the research focuses on post-disaster impacts, special consideration must be given to avoiding unintentional harm in the community. Guidance from community partners is essential in order to understand the context and conduct the research in a way that is appropriate for the community circumstances. The following table summarizes the principles of CBPR outlined by Israel and colleagues *(37)*.

**Table 4.12.2 Principles of Community-based participatory research (CBPR) (37)**

| Principle | Explanation |
|---|---|
| **Acknowledge the community as a unit of identity** | Community is not necessarily geographic. One of the defining characteristics of a community is identifying with it. People who identify with a community feel a sense of belonging based on certain attributes. |
| **Research initiatives build on the strengths and resources within the community** | This is what is referred to as a strengths-based or asset-based approach. In collaboration with community partners, researchers identify what assets (see Chapter 3.1) or resources are in the community and build on those strengths. |
| **Facilitate collaborative, equitable, empowering partnerships where power is shared and inequalities are addressed through the research** | The emphasis on collaborative, equitable partnerships is central to participatory projects. Within these partnerships, power is shared through collaborative decision-making. The research focuses on inequalities and social change to disrupt power differentials. |
| **Co-learning and capacity-building for all partners** | CBPR projects emphasize capacity-building within the community and within partnerships. The focus is for people to learn from one another and build capacity within themselves, their organizations and their communities. |
| **Knowledge generation is balanced with intervention activities so everyone benefits** | The knowledge that is generated from research processes must be balanced with intervention activities so that it is mutually beneficial for everyone involved and the community. |

| Principle | Explanation |
|---|---|
| **Locally relevant projects which address public health problems and consider ecological perspectives related to determinants of health** | Partnerships shape the research agenda by identifying locally relevant issues. CBPR projects can be directed toward understanding and acting on determinants of health which contribute to locally relevant health issues. |
| **Foster systems development using a cyclic, iterative process** | By understanding the context of a community and working in partnership with local citizens and organizations, CBPR projects can contribute to systems development or change through an iterative process. As new knowledge is generated, it can be integrated to improve systems within the community. |
| **Sharing the findings and involving community partners in wider dissemination of knowledge** | Knowledge which is generated from the project is shared and partners are involved in knowledge mobilization activities for wider dissemination of the findings. This ensures lessons learned from the project are shared with people who can benefit. |
| **Long-term commitment with consideration of sustainability** | CBPR projects involve long-term processes starting with partnership development, identification of the issues, designing the project components, securing funding, implementing the research activities, analyzing data, and dissemination of the knowledge generated. Partnerships often continue beyond individual projects in the interest of ensuring sustainability and long term system change. |

According to Phibbs and colleagues *(38)*, there is a distinction between top-down participatory approaches and bottom-up community development. The different approaches to working with communities influence working partnerships and relationships between DRR organizations and communities. They write:

"In community-based health promotion, problems, targets and actions are defined by the sponsoring body. The notion of community is relatively unproblematic, with community settings being viewed as venues for interventions that largely target the individual. In these top-down community-based interventions, activities are mainly health, or in this case disaster preparedness, oriented. Community-based initiatives tend to be single issue focused and time-limited, discontinuing once the sponsoring body has withdrawn."

In contrast, an approach focused on community development ensures the identification of priorities, problems and appropriate actions that are determined by the community. Potential power differentials are recognized, empowerment is a priority, and actions focus on capacity building in the community. In a community development initiative,

> ...the target of the intervention may be the community itself or structures, services or policies that impact negatively upon the community by creating vulnerabilities. Activities may be broad-based, targeting wider factors which are associated with negative social outcomes, such as discrimination, poverty or crime, thereby providing

indirect disaster resilience outcomes such as facilitating community empowerment and enhancing social capital *(38)*.

The following case studies provide examples of qualitative research of particular relevance to Health EDRM.

### Case Study 4.12.1
### The EnRiCH Youth Research Team Photovoice Project, Canada

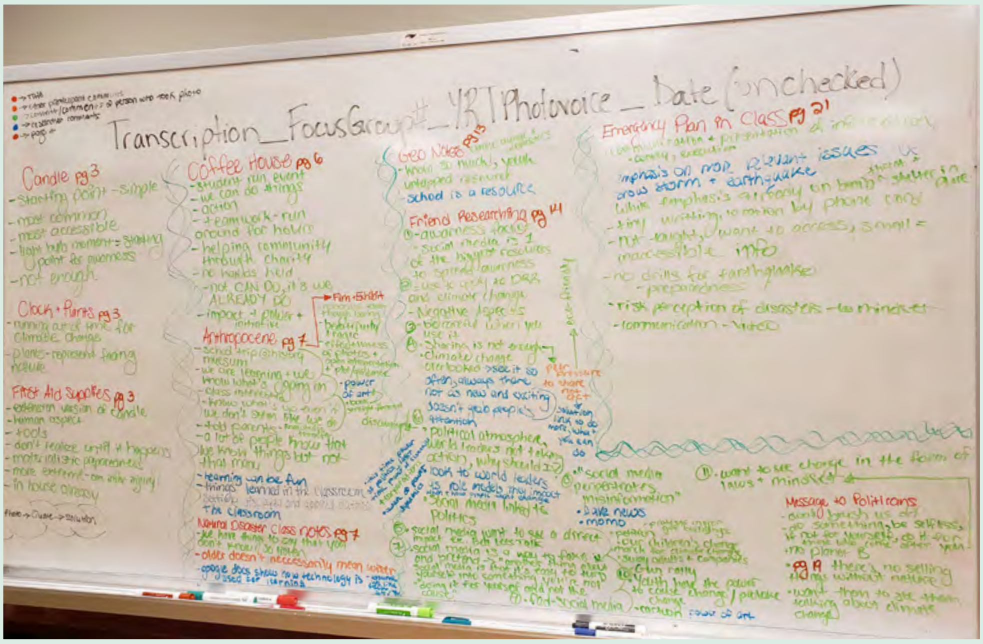
The EnRiCH Youth Research Team is a grass-roots initiative to engage youth in DRR research and action for social change to promote resilient communities. The team has met monthly since 2016, with an annual one-week mini-enrichment course, through a specialty programme offered for high school students by the University of Ottawa. The youth who are members of the team range from 13 to 17 years of age, and they are mentored by undergraduate and graduate university students who are part of the EnRiCH research team. As part of the regular meetings, the youth team members learn about the research team's projects and design and work on projects, including a series of education modules to teach youth about disaster preparedness. When the youth team members heard about the research team's Photovoice project, they asked if they could do their own Photovoice project to express their views about youth engagement in DRR and climate change action.

Photovoice is a qualitative participatory action-based research method used to engage and empower community members to reflect and co-create knowledge with researchers *(39)*. Participants are invited to take pictures of their personal experiences, and express their ideas through picture narrations *(40)*. Participants are actively involved in each of the five steps:

1. Identifying objectives and intended outcomes;
2. Deciding on Photovoice assignments;
3. Taking photographs about the topic;
4. Identifying themes; and
5. Planning a photo exhibition to connect with influential stakeholders in the community *(39)*.

The first Photovoice session for the EnRiCH Youth Research Team was held in March 2019. Over a one-year period, they participated in eight sessions, each lasting two hours, where they shared photos related to youth engagement in DRR, discussed issues and solutions for change, and identified concepts they would like to take photos about for subsequent meetings. The youth team will invite influential stakeholders related to DRR and climate change action to attend their exhibition in 2020, along with leaders and decision-makers in the education system and youth in the area. Figure 4.12.1 shows how the qualitative data were analysed from each Photovoice meeting to bring back preliminary themes for the youth participants to confirm or revise. This is referred to as member-checking in qualitative research and ensures rigour in confirming the themes are representative of the data.

**Figure 4.12.2. Preliminary theme analysis in preparation to report back at the next Photovoice session (EnRiCH Research Lab – University of Ottawa)**



This project underscores many principles of participatory research including:

- Pproject design shaped by the needs and preferences of the community members;
- Focus on existing strengths and resources in the community (see also Chapter 3.1);
- Advocacy and emphasis on social change for a locally relevant issue;
- Co-learning and capacity-building for all partners;
- Collaborative and equitable partnerships where decision-making is shared;
- Sharing of knowledge and involvement of everyone in planning the exhibition and dissemination of the findings.

This initiative has been long-term (supported by two research grants, 2012-2017; 2016-2019) and has required sustained effort to maintain resources and continuity for the youth involved in this team.

### Case Study 4.12.2
### Experiences of the 2010-2011 earthquakes in New Zealand

As community-based participatory research encourages trust on the part of community research partners and has been shown to promote the wellbeing of indigenous communities *(41)*, Kenney and Phibbs *(42)* conducted qualitative research using a participatory approach that encompassed similar principles, in New Zealand. The researchers' partnership with an indigenous Māori tribe, Ngāi Tahu, facilitated collaborative design and implementation of research that explored the earthquake experiences of local Māori following the 2010-2011 Canterbury earthquakes. Project aims included identification and documentation of cultural factors that facilitate Māori health and well-being, and development of recommendations for improving responders' approaches to addressing the psychosocial and health needs of communities, during disasters.

A point of difference with traditional CBPR was that an indigenous Kaupapa Māori research methodology *(43)* shaped the design and conduct of the research. The research was designed by and for Māori, as well as conducted by Māori researchers under the oversight of the local tribe and in accordance with Māori ethical principles *(44)*. Themes arising from the research were confirmed by the community, with the local tribe Te Rūngana o Ngāi Tahu retaining intellectual property rights over the findings and acting as co-authors of publications arising from the research. This process ensured the research became community-led rather than community-based or centred, and strengthened community engagement.

Historically, Māori like most indigenous peoples have used stories to create and ensure the intergenerational transmission of knowledge *(45)*. Contextually relevant narrative research methods which accommodated this process *(46–47)*, were therefore applied to gathering and analysing participant's stories.

Researchers specifically drew on dialogical interviewing techniques to capture participants' viewpoints. Dialogical interviewing *(48)* is an approach that is effective for disrupting power differentials between researchers and participants *(49)*. It is therefore particularly useful for gathering data when researching with marginalized individuals and communities, including, as in this instance, indigenous collectives.

The researchers used thematic analysis to identify discrete stories nested in participants' interviews and analysed the stories using whole narrative unit analysis. Participants' stories were examined to identify contextually complete blocks of texts which were analysed in paragraph format rather than line by line in order to retain the narrative quality of each participant's story. This approach also ensured that analytical findings did not become decontextualized. Narrative analysis highlighted how a nationalized Māori Recovery Network mobilized resources and support to the culturally diverse communities of Christchurch following the earthquakes. Findings showcased ways in which cultural attributes, Māori knowledges, values and practices, interwove to create moral and relational technologies, that when operationalized, addressed the immediate needs and facilitated the health and wellbeing of Māori.

Participants' talk also documented how cultural attributes could be used to enhance the recovery and resilience of the wider Christchurch community.

The prompt and effective disaster risk management approach implemented by Māori, aligns with key recommendations in the Sendai Framework for Disaster Risk Reduction (2015) *(50)*. Māori implementation of best practice in DRR, has generated increased willingness on the part of regional civil authorities, and government to engage and collaborate with local Māori tribes in strategizing for national resilience. To that end, research findings have shaped the development of New Zealand's recently released National Disaster Resilience Strategy *(51)*, as well as informing United Nations disaster science initiatives *(52)*.

### 4.12.9 Conclusions

This chapter presented an overview of different qualitative methods, as well as some of the issues to consider when designing and implementing studies using these designs. We also highlighted the importance of participatory design and collaborative partnerships, distinguishing between community-based and community-development approaches. In Health EDRM, qualitative methods can be used alone, or in conjunction with quantitative methods in a mixed method methodology (Chapter 4.13). Regardless of the overarching design, it is important to be aware of the differences in paradigms for each method and to consider how to minimize power differentials and maximize empowerment when conducting research with communities.

### 4.12.10 Key messages

- **Qualitative research design and methods has an important role in Health EDRM.**
- **Rigour is needed to ensure qualitative research contributions are of high quality and credible.**
- **Community-based research is based on partnerships and shared ownership of projects, where the voice of citizens in a community are valued and represented in the research findings.**
- **Qualitative research design has the potential to fill many research gaps in DRR, building on the fact that everybody experiences disasters differently and that disasters affect everybody in different ways.**
- **The emergent design of qualitative research offers the flexibility to address these complex and differing experiences.**

## 4.12.11 Further reading

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# 4.13

# Addressing complexity through mixed methods

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## 4.13.1 Learning objectives

To understand key factors to consider when developing a mixed methods study for research in health emergency and disaster risk management (Health EDRM) , including:

1. The basic principles of mixed methods research.
2. The relevance of mixed methods design for disaster research.
3. Systems thinking for use in disaster research.
4. The basic tenets of complexity theory and their relevance for disaster research.

## 4.13.2 Introduction

The timing, characteristics and non-linear impacts of different types of disasters contribute to the complexity of prevention, preparedness, response and recovery – as well as to the challenges for designing research relevant to disaster health and Health EDRM more generally. Although warning systems make it possible to anticipate some weather-related events, other types of disasters such as wildfires, tornadoes and pandemics typically provide little warning. For disaster health research, it is rare to see a simple, single research design that can capture the complexity needed for disaster studies, given the dynamic nature of the context around risks, hazards and events leading to a disaster. Mixed methods and a systems approach provide additional options to address some of these issues.

While mixed methods research is typically described in terms of its evolution over the past 30 years, some argue that this approach has been around for at least a century *(1)*. Nevertheless, it is recognized as a third methodology, with its own set of assumptions and criteria for quality *(2–3)* and not surprisingly, its own set of critiques *(1)*.

Mixed methods research combines qualitative and quantitative methods, and grew from the recognition that some research questions require both quantitative and qualitative methods to provide comprehensive answers. This approach is often used with complex problems, when quantitative or qualitative methods are not sufficient on their own *(3)*. Given the challenges of defining mixed methods research, and the historical evolution of this approach, Johnson et al *(4)* asked leaders in research methods to provide a definition. Integrating the 19 definitions they received, they presented this definition:

> “Mixed methods research is the type of research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches (such as the use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purposes of breadth and depth of understanding and corroboration.”

While mixed methods research is common, it is not without critique and practical considerations. Flick *(1)* provides an excellent overview of the myths and mantras, and perhaps the most salient critique is that mixed methods research is somehow regarded as superior to quantitative and qualitative methodologies, despite the limited scope of methods used in mixed methods research (surveys, interviews, for example). Other challenges include defining what is meant by mixed methods research, and how to manage conflicting assumptions, paradigms and values. Criticisms of these studies often include lack of integration of the findings from the quantitative and qualitative arms of the design *(4)* and the need for more comprehensive triangulation *(1)*.

### 4.13.3 Mixed Methods Research Designs

When deciding whether or not to use a mixed methods research design, the first step is to consider the research question *(1)*, which as with all studies should drive the methodological approach (Chapter 3.5). Generally, complex questions require more complex methods. Simple research questions are characterized by having one concept or variable of interest, and one type of data needed to answer it. Complex questions have multiple concepts or groups, and changing trajectories. More than one type of data is needed to answer the question *(5)*. Once the research questions are in place, the most appropriate and feasible methodologies can be identified. In doing so, it is essential to be aware of theoretical and epistemological differences between the quantitative and qualitative methods being considered *(1)*.

In developing the design, researchers must decide whether the main method needed is quantitative or qualitative and how the supplementary method will support their analyses *(6)*. Palinkas and colleagues *(7)* and Creswell and Plano Clark *(8)* provide excellent overviews of different types of designs. They use capital letters (QUAN or QUAL) to indicate the weighting of the main method, and lower case letters to indicate the weighting of the other method (quan or qual), and the → or + symbols to indicate whether the methods will be implemented sequentially or simultaneously *(8)*. Table 4.13.1 summarizes different types of designs using this notation, and provides examples relevant to Health EDRM research.

### Table 4.13.1 Overview of mixed methods designs and applications to Health EDRM research

| Design | Structural description | Applied example | Data collection and analysis |
|---|---|---|---|
| QUAN + QUAL | Quantitative and qualitative methods are implemented simultaneously and have the same weighting | Randomized trial measuring behavioural outcomes following a disaster preparedness campaign using a community survey and telephone interviews with a subset of the survey sample | QUAN: Analysis of numerical survey responses on a Likert scale<br>QUAL: Thematic analysis of interview data |
| QUAL + quan | Main method is qualitative, implemented simultaneously with quantitative method which is weighted less | Focus groups with citizens who have experienced flooding of their homes, supplemented with a short survey related to accessing mental health services | QUAL: Iterative content analysis of focus group data<br>quan: Analysis of binary responses (for example, yes and no). |
| QUAN + qual | Main method is quantitative, implemented simultaneously with qualitative method which is weighted less | Exit survey with citizens attending influenza vaccination clinics, supplemented with field observations of crowd control and dynamics of the flow of service delivery | QUAN: Analysis of Likert scale ratings from survey<br>qual: thematic analysis from 2 observers field notes |
| quan → QUAL | Supplemental method is quantitative, implemented before the main qualitative method | Questionnaire sent to participants before a table top exercise to identify priority topics for discussion, followed by field observations and thematic analysis of the discussions during the exercise and debriefing sessions | quan: Analysis of ranking of topics.<br>QUAL: Thematic analysis and triangulation of field notes taken by observers with transcripts of discussions. |
| qual → QUAN | Supplemental method is qualitative, implemented before the main quantitative method | Key informant interviews to pilot test items for a health risk perception survey being administered to first responders following a prolonged response to wildfires | Interview data analysed deductively according to a coding grid based on topics from the risk perception survey |
| QUAL → QUAN | Quantitative and qualitative methods are weighted equally, but the qualitative method is implemented first | Community consultation focus groups followed by a community survey to set priorities for a public health action plan | Inductive thematic analysis of focus group data to identify priorities, followed by ranking of priorities |

| Design | Structural description | Applied example | Data collection and analysis |
|---|---|---|---|
| QUAN → QUAL | Quantitative and qualitative methods are weighted equally, but the quantitative method is implemented first | Rapid needs assessment survey distributed to households impacted by a chemical spill, followed by focus groups with a subset of the population who are at heightened risk | Standardized post-disaster survey analysed to identify neighbourhoods disproportionately impacted using GIS mapping; subsequent outreach and exploratory data collection and analysis to understand short-term health impacts |

In the case of intervention research, Minary et al *(9)* provide a framework to guide evaluation design for complex interventions, as well as considerations for evaluating effect, implementation and how mechanisms and context interact to determine intervention outcomes. Further information on the practical considerations for designing mixed methods research studies is available elsewhere *(7, 10–11)*. An important decision to consider in the design stage is how best to ensure comprehensive triangulation, which goes beyond integration of different types of data *(1)*.

### 4.13.4 Considerations for design and implementation

When combining qualitative and quantitative methods, it is important to consider how the different paradigms will be reconciled *(2)*, and to be certain of the rationale for using mixed methods research to answer the research questions. The mixed methods research design is often methods-centric, with the focus on combining specific methods (for example, quantitative surveys with qualitative interviews) at different timepoints in the project *(1)*. Typical design decisions include determining whether the data will be collected and analysed at the same time, or separately and integrated later.

The decision to do mixed methods research should come after the research questions are identified. It is often described as the obvious choice, under the assumption that two methods are better than a single method *(1)*. This assumption has infiltrated funding programs where mixed methods research projects are deemed more comprehensive. However, as Flick *(1)* emphasizes, most such studies use limited qualitative methods (such as interviews) and don't explore the range of qualitative methods. When applied to a disaster health research context, this can limit creativity in addressing complex issues.

It is important to consider how theory and epistemological differences will be managed in mixed methods research *(1)*. Morgan *(12)* defined research paradigms as "systems of beliefs and practices that influence how researchers select both the questions they study and methods that they use to study them". Paradigms are guides for researchers to determine how to approach a research topic, including the research questions, design, methods and analyses. A pragmatic paradigm is most widely used in mixed methods research *(13)*. When doing multiple methods (separate studies not mixed), this task is simpler because the paradigms are acknowledged for each method and presented separately.

The function of the mixed method study will determine how the qualitative and quantitative methods are combined at the interface point *(3, 6)*. When determining function, it is important to consider whether the methods need to be combined to answer the same research question, or whether a series of research questions related to the topic require mixed methods. The need for triangulation is a common reason for choosing mixed method design. Flick *(1)* provides a good overview of how triangulation has evolved in recent decades, beyond confirming, disconfirming and expanding findings.

The findings of mixed methods research can be integrated in different ways and at different times. O'Cathain and colleagues *(14)* provide practical suggestions for how to follow a thread and move back and forth between the quantitative and qualitative datasets to confirm or expand the analyses. Use of a mixed method matrix is another option for identifying patterns in the different datasets. Publication of triangulation protocols is an important contribution for the literature, because these enable readers to understand at what points the datasets were integrated and what steps were followed.

Johnson and Schoonenboom *(11)* present a series of tables suggesting different ways qualitative methods can be combined with quantitative methods to enhance randomized trials (Chapters 4.1 and 4.3). In the early stages of designing a randomized trial, qualitative approaches can be used to establish the fit of a conceptual framework or theory (Chapter 4.10) for the intervention. They can also be used to gather information about the context in which the intervention will be implemented and engage stakeholders. For complex interventions, mixed methods research can be used to evaluate outcomes and implementation *(9, 14)*. Qualitative methods are often used in the process of constructing or piloting surveys or other data collection instruments. They are also frequently used to add depth to quantitative designs, such as the example in Case Study 4.13.1 where interviews supplemented survey responses following an earthquake to provide more in-depth understanding of survivor perceptions.

### Case Study 4.13.1
### Perceptions of earthquake survivors in Amatrice, Italy *(15)*

A series of devastating earthquakes occurred in Central Italy in 2015-2016. In the town of Amatrice, 238 people died out of a population of 2500 people. Massazza et al. *(15)* conducted a mixed methods research study with earthquake survivors in the town, publishing their results in 2019. They explored how survivors perceived the damage from the earthquake and how those perceptions aligned with the concept of natural versus human-made disasters.

Massazza and colleagues *(15)* used a mixed methods, longitudinal design which included quantitative surveys and interviews conducted at two time points, 16 months apart. At the first time point, they received 127 responses to the survey and recruited 52 of the survey respondents to participate in one-to-one interviews. The follow-up survey was completed by 112 of the original respondents. The mixed method design allowed the researchers to triangulate the findings from the quantitative data with narrative data from the qualitative interviews. The qualitative data was also used to corroborate and expand the analyses for indepth understanding of the complexity of perceptions and understandings of natural versus human-made disasters.

As an excellent example of how mixed methods can be presented together, Massazza and colleagues *(15)* present a summary of the quantitative results in text, tables and graphs, followed by a detailed explanation of the emergent themes from the qualitative data. The discussion includes points of convergence, divergence and how the indepth thematic analysis expanded understanding of the quantitative results.

As an intervention is rolled out, qualitative methods can be used to assess fidelity of the implementation, to determine the extent to which the protocol is being completed as intended *(11)*. Context is important for understanding the mechanisms of why an intervention works and in what circumstances *(16)*. Qualitative approaches provide distinct options for generating process-related data, which can be used in the interpretation of the success of an intervention.

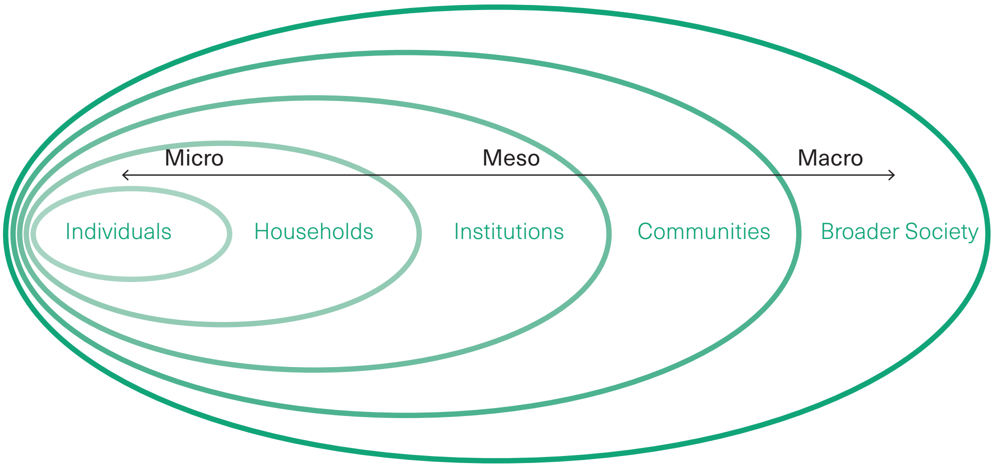
### 4.13.5 Systems thinking and complexity

Most disasters are complex and involve collaboration across different sectors, organizations and jurisdictional boundaries. The type of disaster will determine which organizations and jurisdictions must be involved in planning for Health EDRM, including prevention, preparedness, response and recovery, and, therefore, in disaster research. For example, in research related to influenza pandemics, it is essential to consider the roles and impacts on the health and social services sectors, and also on essential services sectors (for example, hydro, transportation) which are likely to experience operational disruptions when absenteeism is high *(17)*. With this in mind, it is useful to look at disaster health research questions through a systems lens, and to acknowledge the complexity in the design of research projects, particularly the interventions (Chapter 3.3).

Systems are made up of different interdependent components and actors or stakeholders. They can be complex, depending on how tightly-coupled the interdependencies are *(18)*. Systems thinking has gained recognition in various fields, because it can be used to understand context, mechanisms and outcomes. It is a way of examining how things are connected within a whole and how the parts within the whole interact in complex ways *(19)*.

Berry and colleagues *(16)* defined systems thinking as “a set of ‘synergistic analytic skills’ used to help describe a complex set of interacting factors that produce outcomes, to predict their behaviour and to formulate interventions to achieve desired (and avoid pernicious) results”. It enables disaster researchers to examine an issue in terms of a dynamic, interconnected collection of components; recognizing how macro, meso and micro level factors influence its operation *(20-22)*. Micro level factors are associated with individuals or households, whereas meso and macro levels refer to factors at the organizational or community and societal levels, respectively (Figure 4.13.1).

Figure 4.13.1 Multiple Levels for a Systems Approach



Complex research questions require methods that will unpack various influences that interact across multiple levels of society. For example, to achieve a comprehensive understanding of how intervention strategies promote influenza vaccine uptake, it is necessary to have knowledge about people, organizations, communities, health care policy and media; and how different variables intersect across micro, meso and macro levels. The complexity of vaccine uptake across a population includes how messaging influences preventive health behaviours, how social factors influence access and awareness, how mass vaccination is coordinated at the organizational level to increase accessibility, political climate, availability of subsidized health care, and social media threads circulating at the macro societal level *(17)*. The complexity of interdependencies across different levels of the system is the essence of why this problem requires systems thinking.

Complexity has been discussed in the literature for many fields. Cilliers *(18)* outlines different tenets of complexity that are characteristic of complex adaptive systems, including dynamic context, interconnectivity, emergence, self-organization, adaptability, feedback loops and non-linearity. Because complex adaptive systems are open and interact with their environments, the environmental context is inherently dynamic. Systems are composed of different parts and actors which are interconnected, meaning that actions within individual components of a system lead to changes which emerge in other components and the whole system *(19)*. The changes at different levels of the system are non-linear and are, therefore, unpredictable and it is difficult to trace the original causes *(23)*. Nonlinearity is one of the reasons that mixed methods research is important for Health EDRM.

As described by Cilliers *(18)*, complex systems have the capacity for self-organization "… which enables them to develop or change internal structure spontaneously and adaptively in order to cope with, or manipulate, their environment". In the absence of structure or protocols, self-organization naturally follows change in social systems, with people within the system creating structure or strategies to adapt and preserve system functioning. The impacts of changing context within a system are non-linear and feedback loops provide important information about operational functioning *(18)*. In the example of pandemic vaccines, social media provides a salient example of how self-organizing works. When accurate, timely information is missing, people will look for information and share what they find. This has implications for the rapid spread of misinformation, which can influence beliefs and vaccine uptake.

Table 4.13.2 shows an example of how complexity theory can be applied to understand or map out issues within a pandemic context. Social networks are used as an example, but the same table could be created to examine other issues related to the complexity of pandemics (for example, vaccination or supply chain management). This technique can be used for integration in the analysis phase of mixed methods studies, to understand how complexity manifests within a given research topic and needs to be considered in intervention design (see Case Study 4.13.2).

### Table 4.13.2 Application of complexity theory to social networks in pandemic prevention, preparedness, response and recovery

| Tenet of complexity | Application |
|---|---|
| Interconnectivity | Interconnectivity is inherent in relationships, partnerships and strong social networks. Effective pandemic response is dependent on actors from different parts of the health system working together; communication, which is a connective activity is central in pandemic prevention, preparedness, response and recovery. |
| Dynamic context | Social networks are dynamic. People change positions, retire or meet new people, and the relationships within the network change. People also develop new expertise and experience, which contributes to the dynamic nature of the entire system. |
| Emergence | Knowledge and ideas emerge within social networks. Behaviours also emerge and influence social norms within networks – both positive and counter-productive. Emergence can spark innovation and contribute to different intervention strategies. |
| Feedback loops | Social networks provide opportunities for feedback from different parts of the system. This feedback loop creates opportunities for networking, relationship building, and co-learning. |
| Self-organization | Networks contribute to self-organization in the absence of clear policies or plans which outline roles and responsibilities. When structure and information are needed, but missing, people self-organize to create structure and fill the gaps. Self-organization can support pandemic response and recovery, but in vaccination campaigns, it can also hinder formal processes and awareness campaigns if not managed. |
| Non-linearity | Social networks are non-linear. Social media is a good example of how social networks do not develop in linear patterns. Communication and influence within social networks are dependent on the relationships and connections of each actor. Non-linearity prohibits cause-effect relationships from being established. |
| Adaptability | Networks contribute to adaptability. They create opportunities for learning and innovation. Actors within social networks provide different sources of information to enhance situational awareness. |

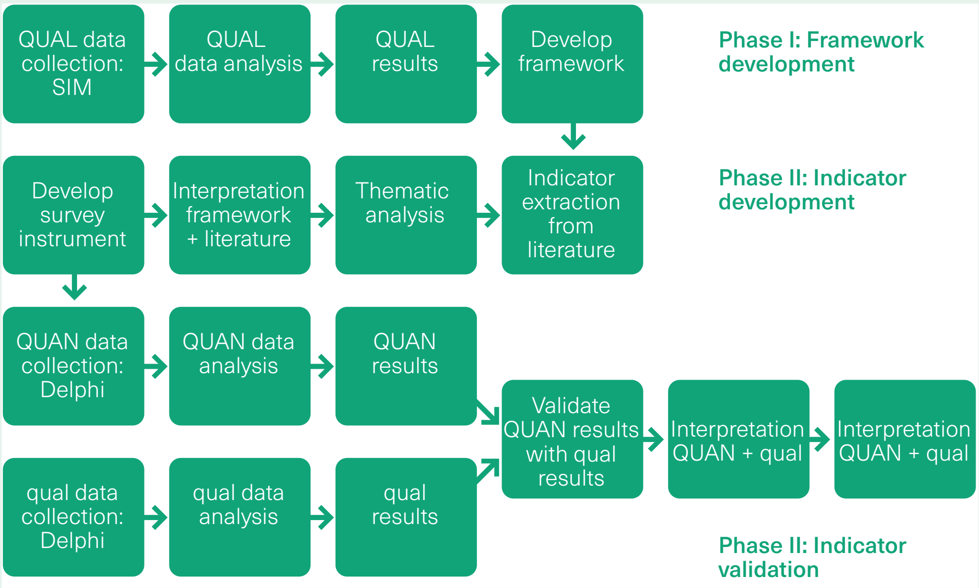
### Case Study 4.13.2
### Advancing performance measurement for public health emergency preparedness (24–25)

An important knowledge gap in Health EDRM is understanding levels of preparedness or readiness in advance of a disaster. This is a challenging topic, but one of important policy relevance, given the increasing frequency of emergencies and the value of defining and measuring preparedness to guide improvement. This topic was well-suited to a two phase mixed methods study to address the dual objectives: "how do we know if we are prepared?" and "how do we measure it?". Furthermore, using mixed methods enables a consideration for complexity, which is seen as increasingly important for public health systems research *(22)*.

The initial exploration aimed at defining emergency preparedness for the public health system in Canada was achieved using a qualitative study design. Rich qualitative data was analysed using a complex adaptive systems lens to develop a framework defining the essential elements of a resilient public health system *(24)*. The framework reflects the complexity of the role of the public health sector in emergencies and was used to ensure that the approach to measurement considered what the system is aiming to do.

The framework elements informed a mixed methods Delphi survey to develop indicators for public health emergency preparedness (PHEP) *(25)*. The Delphi is a mixed methods research technique well-suited to fields where there is a paucity of evidence, such as PHEP research, and is a structured and rigorous approach to collecting data on expert opinion *(26)*. Its use for developing indicators for clinical contexts such as cancer care also rendered it appropriate for developing PHEP performance indicators *(27)*. In the Delphi process, the combination of deductive thematic analysis of the literature, open ended questions for comments on indicators and suggestions for new indicators, and quantitative rating of indicators enabled the development of a list of preparedness indicators *(25)*. The sequence and combination of mixed methods approaches for the two phases is displayed in Figure 4.13.2.

**Figure 4.13.2 Mixed methods used in defining a framework and developing performance indicators for public health emergency preparedness (24–25)**



Interdependencies are the norm in modern society and are the reason systems thinking is useful for disaster health research. Lechner and colleagues *(28)* provide a salient example of the interdependencies between the digital society and financial institutions, which has substantial implications in a disaster context. A digital crisis can trigger a financial disaster as the cascading impacts jump between sectors. This complexity underscores the need for collaboration across disciplines and sectors to support situational awareness *(24)*. Expansive, diverse expertise on collaborative teams can also support integrated knowledge translation, which facilitates diffusion and uptake of research findings *(11, 24)*.

The need to understand context is widely acknowledged in the evaluation literature. In fact, the literature base on realist evaluation underscores the importance of understanding context and how it interacts with a mechanism to influence particular outcomes *(29)*. In supporting this point, Johnson and Schoonenboom *(11)* emphasize the utility of qualitative methods to support quantitative methods in process evaluation, with context being a critical consideration. The integration of concepts of complexity, disaster health research and mixed methods approaches are described in the above example of Case Study 4.13.2.

## 4.13.6 Conclusions

This chapter has introduced mixed methods research design, systems thinking, and shown how complexity can be addressed in Health EDRM research. When conducting mixed method research, it is essential to consider the theoretical and epistemological differences of the methodologies being combined. It is also important to develop the research questions before making the assumption that mixed methods research is the most appropriate methodology for the study.

When the decision has been taken to use mixed method research as a methodology, careful planning must be done to plan how best to ensure there is comprehensive triangulation, which includes (but is not limited to) integration of data from different methods. Examples provided in this chapter illustrate some of the different strategies that can be used to approach complex questions with mixed methods.

## 4.13.7 Key messages

- **Mixed methods, which combines quantitative and qualitative methods, has evolved into a third type of methodology which can provide a more comprehensive explanation for the complexity inherent in disaster research.**
- **Systems thinking in disaster health research focuses on the interactions of factors across macro, meso and micro levels of society.**
- **Integration of data, analysis and findings in mixed methods studies is central to the methodology. Many mixed methods studies fall short in the integration process, but this is one of the defining features of mixed methods.**
- **Challenges and practical considerations for designing and implementing mixed method research include theoretical and epistemological differences between methodologies.**

## 4.13.8 Further reading

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# 4.14

# Natural experiments in a hazard context

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## 4.14.1 Learning objectives

To understand the potential utility of natural experiments in health emergency and disaster risk management (Health EDRM), including:

1. Process of conducting a natural experiment in a disaster context.
2. Framework for, and outcomes of, natural experiments.
3. Important strengths and limitations of natural experiments.

## 4.14.2 Introduction

Health researchers are often interested in understanding the effects of certain conditions on health risk or disease outcomes. Typically, constructed and controlled experiments are the cornerstone of studying such causal relationships between exposures and outcomes. An exposure can be any type of condition that is associated with an outcome of interest. For example, the efficacy of influenza vaccine (exposure) can be analysed in relation to the frequency of influenza illness (outcome). In the context of traditionally designed medical experiments, such as randomized trials, exposures are manipulated and are often termed 'treatment'. By contrast, natural experiments are characterized by exposures that are unexpected and cannot be controlled nor manipulated. This exposure may still be referred to as 'treatment' since it essentially performs the same role as the treatment in a randomized trial. Chapter 4.1 explains how to design, conduct and interpret randomized trials in the context of Health EDRM. This chapter discusses natural experiments, an alternative method for studying causal associations. The key components of a causal framework for natural experiments are briefly described in table 4.14.1.

Table 4.14.1 Main components of natural experiments

| Component | Description |
|---|---|
| **Exposure/ treatment** | 'Exposure' broadly refers to any factors (biological, behavioural, lifestyle, environmental) that are being studied in relation to an outcome of interest. 'Treatment' is a technical term that embraces a variety of exposures that differ across experimental groups. In natural experiments, exposures are often disasters caused by natural hazards or anthropogenic (human-instigated) hazards that are typically outside the researchers' control (for example, earthquake, weather shocks and conflicts), and may still be referred to as 'treatment'. |
| **Outcome of interest** | 'Outcome' is a generic term for the various results that are being investigated in relation to a particular exposure or treatment. In epidemiological and health research, outcomes usually refer to incidences of diseases and health risks. In natural experiments, the hypothesized or observed effects of natural and anthropogenic hazards can be studied as outcome variables. For example, cancer (outcome) can be studied among the population exposed to radiation as a result of breach in a nuclear power plant. |
| **Treatment group** | The treatment group describes those people who are assigned to receiving the experimental treatment. In natural experiments, treatment groups are exposed to natural or anthropogenic hazards not by design or deliberate random assignment, but by chance. The treatment unit may be individuals or clusters of people according to affected geographical or jurisdictional borders, regional policies or household units. |
| **Control group** | The control or comparison group serves as a reference group in an experiment. In randomized trials, people in the control group might be given the existing best treatment or a placebo, instead of the treatment being tested. In natural experiments, the control or comparison group may be less exposed (or unexposed) to a hazard than the exposed or treatment group since there may be a range of exposure types or concentrations. |
| **Instrumental variables** | Instrumental variables are a proxy measure for the independent variable of interest. In the natural experiment context, instrumental variables are often used when the exposure or treatment is difficult to directly measure or quantify (see Case Study 4.14.3). Alternatively, instrumental variables may be related to other variables that could independently influence the outcome (for example, unobserved factors or factors that are not directly included in the model), but may still influence the outcome (see below for an example using *(1)*). |
| **Confounding factors** | The exposure-outcome relationship can be influenced by factors that are associated with both the exposure and the outcome. For example, when studying the efficacy of influenza vaccine on reducing the occurrences of flu related illnesses, chronic medical conditions in patients can be a potential confounder (example adapted from *(2)* ). Patients with chronic medical conditions or compromised immune system are more likely to be vaccinated (association with the exposure) and more likely to contract influenza viruses (association with the outcome). However, the chronic conditions are unlikely to be directly on the causal path (that is, influenza vaccination can cause chronic illnesses, which in turn, can cause influenza illnesses), and not being directly on the causal pathway is an important condition for a confounding variable *(3)*. In observational studies, any presence and effects of confounding factors need to be taken into account when analysing causal relationships. |

A traditional randomized trial design exhibits at least the following three characteristics: 1) random assignment of people into the exposure/ treatment and control/comparison groups; 2) researchers' having and exercising control over exposure/treatment assignments; and 3) comparison of outcomes between exposed and control groups. The mechanism of randomly assigning people into exposure/treatment and control groups is of fundamental importance, as it implies that, on average, people across these groups are similar to each other in both known and unknown pre-exposure characteristics *(3)*. This pre-exposure equivalence ensures that any confounding effects from factors that are related to both the exposure and the outcome of interest are balanced across the groups and removes the need for including confounding variables in models and explicitly analysing their effects. Despite this appealing feature, the traditional experimental design is not always a feasible or a practical option. For instance, it would be impossible to control and unethical to simulate a disaster.

Disasters and hazards of various kinds are occurring more frequently and in greater severity. With the world's rapidly expanding and dispersing population together with the impacts of global environmental change, these disasters have greater potential to significantly impact our planet's environmental integrity and its people's health and wellbeing *(4)*. Such occurrences alter the way people live and respond in the affected areas on a scale that would often be logistically or ethically implausible to implement a study using traditional experimental designs *(4)*. Yet, robust evidence-based and informed strategies are needed to serve the affected populous and their environments, together with those experiencing similar events elsewhere or in the future. Natural experiments are, by design, adaptations of conventional approaches or novel methods in providing this evidence-base for Health EDRM. Concordantly, there has been a dramatic increase in the implementation and publication of studies purporting to use natural experiment designs, although their internal validity varies greatly *(5)*.

The randomized trial design is often posited as the minimal standard in considering causation of an effect. However, conventional random assignment, which is the hallmark of randomized trials may be impossible in the disaster context. Nonetheless, it is still possible to have populations that can be demarcated into exposure (treatment) and control groups via a mechanism that is (nearly) as good as random assignment *(6)*. When there is a well-defined exposure that can be contained within a sub-population, and this sub-population is exposed as if in a random assignment, then the natural (or quasi-natural) experimental framework can be used as an alternative to the randomized trial design to infer cause and effect. This chapter follows the convention of Dunning *(5)* and refers to the assignment mechanism that results from an accidental exposure of certain groups of people and which is as good as random as being an 'as if' random assignment. An exposure to a natural or human-instigated (anthropogenic) hazard is an example where natural experiments have been used to understand their impacts on a subject population. This chapter looks at how natural experiments can be used in a hazard/disaster context and the strengths and limitations associated with the framework.

### 4.14.3 Natural experimental framework

The natural experimental framework has embedded in its structure many of the elements that characterize randomized trials. These include the exposure, control and outcomes that are outlined in table 4.14.1. When a disaster occurs, such as an earthquake, a well-defined exposure can then be defined which is known to affect all people within a particular perimeter. These people can be considered as comprising the exposed group. Those outside this perimeter remain unaffected and can be categorized as the unexposed, control or comparison group. In some cases, the level of exposure may vary across people and those who are less directly affected may also need to be considered in the analysis.

The focus of using and reporting a natural experiment should be on establishing validity and making a plausible argument for a treatment assignment that is as good as random, or for the difference in exposure of two or more groups. The onus is on the researcher to make a compelling argument for the credibility of 'as if' random assignment by providing both quantitative and qualitative evidence. In a natural experiment with a persuasive 'as if' random assignment argument, the groups are assumed to be similar in all pre-exposure characteristics including any confounding factors, as in the case for true randomization. However, natural experiments are in fact observational studies as the manipulation of 'treatment' cannot be controlled by the researcher as in a true experiment. It is important to distinguish natural experiments from other observational studies, such as quasi-experiments and matching designs (Chapter 4.5), where assignment is neither random nor 'as if' random and hence confounding (both observed and unobserved) becomes an issue to the validity of causal inference *(5)*. In such cases, the effects from confounding factors may need to be explicitly taken into account by adding the confounding variables to the outcome-exposure model and analysing their effects on the association.

In a natural experiment with convincing 'as if' randomization, the data analysis is often simple and interpretable. It usually involves comparing the estimated outcome means between differently exposed groups. For instance, when analysing the level of anxiety after an earthquake, the average effect can be estimated by the average level of anxiety (measured using some form of testing) for all those who experienced the earthquake (by some definition) compared to those who were unexposed to the earthquake. In some natural experiments, exposure/treatment assignment happens at the cluster level (for example, policy implementation in cities, jurisdictional borders or natural boundaries) related to the exposure under consideration. The simplest approach to analyse the average causal effect is to use the average cluster means (that is analyse at the level of random assignment). For example, when analysing the efficacy of a district-wide policy roll-out which affects everyone within the district but not those outside the district boundaries, the average effect is estimated by comparing the average outcomes across different districts rather than across individuals. Sometimes, this is not possible and more sophisticated approaches are needed (see *(5)*).

Three key elements are considered in a typical process for implementing a natural experiment: study design, statistical analysis and validation.

## 4.14.4 Study design

Exposure-outcome causal model is defined and causal parameters of interest are determined. The 'as if' random assignment argument is also validated using suitable quantitative and qualitative methods. At this point, research hypotheses around the effects of exposures can be considered and formalized.

## 4.14.5 Statistical analysis

When assumptions around 'as if' random assignment and other model assumptions related to analysing experiments are met, the Neyman–Rubin potential outcomes model is often applied (*7*). One important model assumption is the 'non-interference' assumption: the independence of the effects of exposures across participants, that is, the effects of exposure on one individual do not influence the effects of exposures on other participants and vice versa. Another key assumption is the 'excludability': the effects of exposure on the outcome depend only on the exposure itself and not on other features of the experiment. In a strong natural experimental design, the average exposure/treatment effect is estimated by the difference between average values of observed outcomes for all participants in the exposed groups compared to those in the control/comparison group.

## 4.14.6 Validation

Quantitative methods are available to test the assumptions about similarities in pre-exposure characteristics between the participant groups. Hence, before the exposure, numbers of participants in each sex, demographic, and other socioeconomic backgrounds are balanced across the exposed and comparison groups almost as if they were randomly assigned to these groups.

Qualitative knowledge about context and process is equally crucial for establishing internal validity in treatment assignment, the integrity of exposure-outcome causal model and the assessment of model assumptions such as non-interference and excludability. Qualitative knowledge is also essential for reporting and assessing external validity such as in replicability and generalisability of results.

## 4.14.7 Natural experiment designs and their applications

Disasters due to natural hazards often strike with little or no warning and can impact on any population regardless of their attributes, which render disasters persuasive circumstances for implementing a natural experimental design. Perhaps not surprisingly, the natural experimental framework has increasingly been used in broad natural/anthropogenic hazard contexts. For example, the framework has been extended to analyse the impact of arguably one of the most critical natural and anthropogenic hazards that we face today: climate change. Case Study 4.14.1 illustrates a study where children's wellbeing outcomes (measured by undernourishment, labour force participation, and adequacy of medical attention) were analysed in the aftermath of devastating Hurricane Mitch in Central America (October-November 1998).

## Case Study 4.14.1
## Children's vulnerability to weather shocks: A natural experiment *(8)*

Agricultural societies are often more vulnerable to weather shocks such as severe storms and hurricanes. Hurricane Mitch hit the Republic of Nicaragua in the last week of October of 1998, and was one of the most destructive storms ever to strike Central America. It left behind more than 50 inches (1.27 metres) of rain and more than 20% of the population was in need of new housing. But, not all municipalities within Nicaragua were directly affected. Fortuitously, a household-level survey had been initiated before the hurricane, the Living Standards Measurement Study (LSMS), which collected data in 1998, 1999 and 2001. Exploiting the LSMS, wellbeing outcomes of Nicaraguan children residing in areas affected by Hurricane Mitch were compared to their unaffected counterparts using a 'double difference' analysis.

The assumption about 'as if' random assignment was made based on the unpredictability of the location of the impact, and that any region was as likely to be on the path of the hurricane as any other regions nearby. The children from households in the municipalities severely affected by the hurricane were analysed as the exposed group. The children from households located outside these areas were used as the comparison group. Validity checks were performed using both quantitative and qualitative methods. The characteristics between the exposed and less exposed households were analysed to validate the 'as if' random assignment argument. Rural areas were more directly hit by the hurricane and the differences in median income and parental educational attainment were detected between the exposed and less exposed groups. These differences were controlled once the treatment effect was conditioned on location. The households were used as the instrument for assigning children into exposure groups. This implies that, after conditioning on location, the outcome of interest (demand for education and health services) was only influenced by whether the households were directly exposed to Hurricane Mitch or not, and not by other underlying household characteristics or other unobserved factors.

Qualitative checks were also performed to analyse the disruption in the supply of school and health services due to the hurricane, as this was considered a potential confounding factor for the demand for those services. The study found that children living in the regions affected by Hurricane Mitch were 30% less likely to be taken for medical consultation when sick, experienced 8.7% increase in the probability of being undernourished, and had 8.5% increase in labour force participation. Although the randomization unit was at the household level, the analyses were performed at the individual child level. The correlation between children within the same household needs to be taken into account when computing variability estimates. However, the extensive validity checks performed in this study to assess the 'as if' random assignment argument were exemplary.

Novel ways of adapting natural experimental designs are continuously being devised. One illustration is a study looking at the application of natural experiment to evaluate cyber security policies *(9)*. Digital hacking is a relatively new type of man-made security hazard that could place huge cost and burden on people and systems at a global level. Much investment has been made by many countries and organizations on building capacity to deal with any potential breach in cyber security and yet, testing such systems is challenging. Natural experiments are proposed as an alternative to costly and, in some cases, unethical application of traditional experimental design in evaluating the integrity of such programmes.

### 4.14.8 Regression-discontinuity design

Regression-discontinuity designs are natural experiments where treatment assignment depends on a certain threshold value of a variable (Chapter 4.5). For example, patients may receive a new type of drug depending on their measure of blood pressure being above a certain cut-off value. Around the levels very close to this cut-off, the patient characteristics may not differ greatly even though they are assigned into two distinct groups: those who receive the new drug and those who do not. It can be graphically characterized by a jump or break in the trend for the probability of receiving a treatment versus control around this value of the variable. The 'as if' random assignment argument is only plausible for cases around the near neighbourhood of this threshold as observations farther apart are likely to differ more systematically. In the above example, patients with blood pressure much higher than the cut-off value are likely to have very different lifestyle characteristics than those with values much lower than the cut-off used. So any observed differences between the outcomes being studied may be due to these lifestyle differences rather than the new drug. Case Study 4.14.2 is an application of a regression-discontinuity design for studying the changes in people's lifestyle choices and provision of healthcare services as a result of the 2011 Great East Japan Earthquake (Chapter 1.3) *(10, 11)*.

#### Case Study 4.14.2
#### Residential relocation and obesity after a disaster: A natural experiment from the 2011 Great East Japan Earthquake and tsunami (adapted from (11))

Residents in a neighbourhood typically share common demographic characteristics or lifestyle patterns. However, when the east coast of Japan was hit by a massive earthquake and tsunami in 2011, a large-scale exodus ensued that could not have been foreseen nor planned. Approximately 345 000 people were displaced from their homes, disrupting their normal way of life and possibly their long-term wellbeing. This disaster was used as the 'as if' random assignment mechanism where the outcomes of survivors before and after the earthquake were compared. Coincidentally, a nation-wide cohort study of ageing population, the Japan Gerontological Evaluation Study, had been established seven months before the earthquake, allowing the researchers to investigate the impact of disaster in comparison to the extensive pre-disaster information available on the cohort.

For example, the cohort was followed up about 2.5 years after the disaster to study the impact of relocation on 3594 participating survivors' weight gain measured using the Body Mass Index (BMI). The change in the distance to the nearest food outlets, bars, supermarkets was used as an explanatory variable in a fixed effects multinomial logistic regression model. Various covariates such as age, socioeconomic status and mental health and behaviours were also added in the analysis. Adjustments for confounding variables are necessary if systematic differences between the survivors pre- and post-disaster are to be assumed. The study found that moving 1km closer to supermarkets, bars or fast food outlets increased the odds of BMI change from normal to the obese range by 1.46 (95% confidence interval (CI): 1.15 to 1.86), 1.43 (95% CI: 1.11 to 1.86), and 1.44 (95% CI: 1.12 to 1.86), respectively. Such findings suggest that the impact of a disaster on survivors' lifestyle choices is of pervasive nature, and could have long-term health and wellbeing implications.

The discontinuity in Case Study 4.14.2 is at the point of the disaster, when changes can occur and differentiate people's post-event characteristics from those of before. Around the time of event, the probability of being exposed to certain risks can be higher for people within the vicinity of the disaster compared to those further away. Some changes, such as the residence displacement, will likely be irrevocable, and the consequences of those can be analysed as illustrated in Case Study 4.14.2.

In Chapter 2.4, Case Study 2.4.1 described an example in which the impact of moving toward a more integrated health system on emergency room attendance and acute admission rates was analysed for the population affected by the 2011 Christchurch, New Zealand earthquake *(12)*. Figure 2.4.1 in Chapter 2.4 shows visible breaks in the trends for emergency room attendance and admission rates before and after the earthquake.

## 4.14.9 Instrumental variables design

Instrumental variables are proxy measures for the actual variable of interest that may be difficult to measure or could lead to biased estimation. In instrumental variables design, people are assigned at random (or 'as if' random) to this proxy for the variable of interest. For example, Angrist *(1)* sought to measure the long-term labour market consequences of those veterans who served in the military during the Viet Nam era compared to their nonveteran counterparts. Here, military draft eligibility was used instead of actual military service in a natural experiment design which produced robust unbiased estimates. Using the military draft eligibility as an instrumental variable ensured that all those who were subject to randomization were analysed rather than those who complied with the assigned treatment (that is, completed military service). Furthermore, those who volunteered to serve or those who did not pass the health tests after being randomly selected for draft eligibility would have had different characteristics to those who did not serve in the military. So, it was important to use the draft eligibility, which was closely associated with actually serving in the military, but also would not otherwise influence an individual's lifetime earnings.

Case Study 4.14.3 *(13–14)* explores prevalence of iodine deficiency disorders that are endemic to areas characterized by subducting plates in the Himalayan region. Iodine deficiency is a disaster that is not sudden, but is easily preventable. It is a devastating issue in many communities due to its link with high levels of infertility and miscarriages, cretinism and lowered cognition, as well as the usually harmless but visible goitre. The research described in the case study focuses on the Baltistan region, northeast Pakistan, before any long-term iodization programmes, where clear regional differences in prevalence of goitre were found north and south of the Main Karakoram Thrust, where Asia and India meet geologically, giving a natural experiment. This experiment is characterized by exposure ('north-south goitre prevalence') that is unexpected and cannot be controlled nor manipulated. It can be argued that selection of individuals was "controlled" precisely on the basis of the north-south goitre prevalence, leading to the outcome of the incidence of iodine deficiency. The geological separation was used as an instrumental variable in categorising two communities by their environmental differences, which were otherwise difficult to quantify (for example, geological and geochemical differences).

### Case Study 4.14.3
### Differences in endemic goitre prevalence in the Karakoram mountains, north Pakistan: a natural experiment suggesting an unrecognized cause (adapted from *(13)*)

Environmental iodine deficiency, of which endemic goitre is one manifestation, causes several disorders, none of which were seen as related to goitre by the local community in Baltistan, northern Pakistan in the 1980s. However, the community noted that more people living in the north of the region suffered from goitre than did those living in the south. Furthermore, goitre was accepted as normal, not triggering clinic visits. Careful qualitative investigation of the communities on both sides of the rivers did not show any north-south differences in ethnicity, diet, farming practices or other obvious causes of the difference. Residence village was used as the 'as if' random assignment mechanism.

New patients attending a clinic fell naturally into four groups: northerners with goitre, northerners without goitre, southerners with goitre, southerners without goitre. There was a significant difference in prevalence due to age-sex and, independently, to residence north or south of the Main Karakoram Thrust. This plate tectonic boundary divides the region into two clearly distinct geologies, and increased the prevalence in the north by 15-18%. A literature search revealed two other studies by another team more than 100 miles to the west, straddling the Thrust. Findings were similar: villagers on the northern plate had consistently more goitre. The geology was the explanatory variable, and indicates that the distribution of iodine deficiency disorders in this and other mountain ranges are likely related to plate tectonics in addition to iodine deficiency.

The study shows most of the strengths in Table 4.14.2. This robust observation allows prediction of the distribution of iodine deficiency disorders which can be tested by further observational studies, with a stronger hypothesis than many of the standard explanations for the occurrence of iodine deficiency disorders, such as leaching of soil iodine by rain or removal by glaciation.

### Table 4.14.2 Strengths and limitations associated with natural experiments for Health EDRM

| Strengths | Limitations |
|---|---|
| No ethical constraints about exposure. | No control over baseline differences in the exposed and less or unexposed groups. |
| Can infer cause-effect when 'as if' randomization can be validated. | There is no random assignment in the traditional sense, which may restrict causative assertions if 'as if' randomization cannot be established. |
| Obviates confounding typical in an observational study. | May be difficult to contain the treatment and control groups within certain temporal and spatial perimeters. |
| Quantitative analysis can be simple and transparent. | May be difficult to isolate an effect of an exposure. |
| Statistical results often easy to interpret. | Exposure/treatment may not be of research relevance or interest. |
| Can be less costly than the randomized trials or quasi-experiments if data already available. | Internal and external validity may be difficult to analyse. |
| Can be tailored to the hazard or disaster. | |
| Possible to analyse the effect of a slow onset hazard. | |
| Possible to plan a prospective study. | |

Countries and jurisdictional borders can form natural clusters. In some cases, they can be used as instrumental variables for studying various social, political, environmental and health related differences across groups. Historical borders and policy differences across countries are usually outside the control of the researchers (that is, exogenous to the model). The administrative and structural differences also mean that the countries are 'as if' assigned to different types of treatments. When applying instrumental variables, it is important to check that the outcome of interest is influenced mainly through the association between the instrument used and the explanatory variable being studied, and not through other factors unexplained by the model. For example, in Case Study 4.14.3, demographic characteristics between two communities were analysed to ensure that the instrument used, which was related to the geology of the region, was what explained the observed difference in prevalence of goitre, and not the demographics.

In another example, the extent of food insecurity across 21 countries was analysed in relation to the economic hardship, measured using the unemployment rate and decrease in wages, experienced during the 2004-2012 European recessions *(15)*. The country-level analyses revealed that both measures of economic hardship were associated with an increased sense of food insecurity. Also taking advantage of jurisdictional and policy differences, the association was further analysed using the level of social protection in each country. The risks of food insecurity associated with economic hardship were mitigated in countries that spent more on provision of social protection.

Similar designs have also been applied in studies looking at the effects of environmental policies implemented at the prefecture- or city-level of governance. Environmental regulations on sulphur dioxide emission and acid rain were put in place across different provinces in China in order to reduce air pollution *(16)*. The resulting changes in the volume of industrial activities in the regulated cities were compared to those of unregulated cities. Similarly, gains in energy efficiency following the roll out of 'Smart City' policies in China (aimed at integrating government services and achieving low carbon emitting and ecologically sound urbanization plans) were analysed and compared across the 'Smart Cities' and control cities *(17)*.

Other examples where country-level policy differences have been used to analyse human-instigated hazards can be found in studies of health risk control policies. The impact of tobacco control policy on cardiovascular morbidity and mortality in the Russian Federation was analysed in relation to other countries without such control *(18)*. Similarly, the implementation of trans fatty acid control policy in the Republic of Austria was used as the setting for a natural experiment where the cardiovascular and coronary heart disease mortality was compared between the population under the regulation and the international control population from countries without the regulation *(19)*.

### 4.14.10 Conclusions

Natural experiments provide researchers with opportunities to investigate some topics of relevance to Health EDRM that are not amenable to designs, such as randomized trials. They have important strengths and limitations for hazard and disaster epidemiology, which are listed in Table 4.14.2.

### 4.14.11 Key messages

- **In natural or human-instigated hazard contexts, implementing the traditional experimental design to study cause-effect relationship can be unfeasible or unethical.**
- **When people are assigned into exposure/treatment and control groups by chance, but in a way that resembles true randomization, natural experiments can be used to infer relationships between exposures and outcomes, just as in a traditional experiment.**
- **The credibility and validity of natural experiments depend on the persuasiveness of the 'as if' random assignment argument. The randomization ensures that the exposed and control groups are similar in their pre-exposure characteristics and hence mitigates the effects of observed and unobserved confounders.**
- **Quantitative analyses of pre-exposure characteristics and qualitative evidence around context and processes are useful for establishing the credibility of natural experiment design.**
- **If the assumption of random, or 'as if' random, assignment is persuasive, then the estimation of causal (or treatment) effect is as simple as taking the difference between the means of outcome from the treatment and control groups.**

## 4.14.12 Further reading

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# 4.15 Monitoring and evaluation

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## 4.15.1 Learning objectives

To understand key factors in the development of studies that focus on monitoring and evaluation (M&E) of Health EDRM interventions, including:

1. Meaning and significance of M&E.
2. Existing M&E frameworks in DRR and health.
3. Methodologies for Health EDRM M&E studies.
4. Challenges in developing Health EDRM M&E studies.

## 4.15.2 Introduction

The relatively new discipline of Health EDRM emerged from the cross-over between health and DRR. Health EDRM is "the systematic analysis and management of health risks, posed by hazardous events, including emergencies and disasters, through a combination of hazard, exposure and vulnerability reduction to prevent and mitigate risks, preparedness, response, and recovery" *(1)*. M&E studies are an important means for assessing the impact of Health EDRM, drawing on lessons from the disciplines of both health and disaster management.

The concept of M&E is widely applied across disciplines and by different organizations. It includes a wide range of investigations, from M&E of the impact of national climate adaptation policies to the outcomes of reproductive health programmes of a local NGO. In general, M&E aims to assess the performance of an initiative, programme, project or intervention and to provide evidence to improve future ones. Monitoring and evaluation are two distinct processes involving different methodologies and techniques. According to the disease-specific M&E toolkit issued by WHO, monitoring is the routine tracking of an intervention's inputs (such as financial resources, staff time, cost of medical supplies) and outputs (such as new health services, improved drug supply system, new skills among health workers), which includes regular record-keeping, reporting and surveillance. Evaluation, meanwhile, is the assessment of the contribution made by the various factors of an intervention given the output or outcome *(2)*. A similar concept of M&E has been applied in DRR, as elaborated in the 2015 Monitoring and Evaluation Framework published by the United Nations Office for Disaster Risk Reduction (UNDRR – formerly known as UNISDR). Definitions adopted by UNDRR emphasize the function of monitoring as providing an early indication on the progress, or lack thereof, of an intervention, and that evaluation should not be an one-time event but should be carried out at several time points in response to evolving needs in relation to the achievement of the intended outcomes *(3)*.

This chapter begins with an overview of some of the available frameworks for M&E, before setting out choices that have to made when developing a M&E study, and concluding with a discussion of the major challenges.

### 4.15.3 M&E frameworks in disaster management and health

The Sendai Framework for Disaster Risk Reduction 2015 – 2030 (Sendai Framework) was adopted on 18 March 2015 at the Third World Conference for Disaster Risk Reduction, in Sendai, Japan *(4)*. The Sendai Framework guides the global direction in DRR until 2030 and its emphasis on monitoring and accountability illustrates the critical role of M&E in relation to disasters. The Framework has seven targets, with 38 global indicators that were recommended by an Open-ended Intergovernmental Expert Working Group for measuring the implementation progress of these targets. National governments are also required to define custom targets and indicators to measure their progress, addressing the four priorities of the Sendai Framework, based on national priorities. UNDRR built the Sendai Framework Monitor Initiative (see Chapter 2.1), under which Member States have to report on the indicators and global assessments *(4)*.

While the Sendai Framework has emphasized the significance of M&E in DRR efforts, M&E is considered a relatively weak area in DRR research. There are a number of possible reasons for this, such as the lack of common terminology and methodology, insufficient training of relevant personnel and researchers and a large range of intervention forms *(5)*. In fact, in disasters, different agencies often have their own M&E frameworks involving different approaches, indicators and outcomes. In 2016, Scott and colleagues *(6)* proposed a common framework for DRR programmes to strengthen M&E quality in this field and suggested three outcomes:

i) whether the ability of participants to employ DRR-related knowledge, innovation, education, communication or technology has been enhanced;

ii) whether the DRR institutional framework has been strengthened (for example, development of DRR policies and strategies, range of stakeholders involved in the process); and

iii) whether the motivation to achieve effective DRR has been improved.

While there are benefits of a common framework, it has to be pointed out that the appropriateness of an M&E system depends on a range of factors, including the level of development in the country involved, the scale and nature of the disaster in question, the capacity of the agency, and the funding sources *(7)*. Notably, existing M&E frameworks in Health EDRM are mainly designed for assessing programme effectiveness and not intended for research purposes. However, they still provide valuable and practical information on the purpose of M&E and the major components to be covered; the following sections provide a brief overview of UNDRR's M&E Framework, WHO's M&E Toolkit for the health component in Health EDRM, and The Sphere Standards .

### UNDRR's M&E Framework

UNDRR's M&E Framework is very comprehensive, with detailed description of terminologies, types of indicators, criteria for selecting indicators, implementation plan, data collection methods and reporting mechanisms *(3)*. The guiding factors contained in the Framework for selecting indicators are:

i) linkage between indicator and expected outcomes;

ii) temporal stability of the definition of the indicator;

iii) availability of data and cost-effective data collection instruments;

iv) comprehensibility of the indicator; and

v) quantitative nature of the indicator.

UNDRR classifies evaluations into formative evaluations (such as needs assessments or process evaluations) and summative evaluations (such as impact evaluations, cost-benefits analyses). Formative evaluations aim to improve implementation quality of the project under evaluation, while summative evaluations examine the outcome and impact of the project. Recommended data collection methods for evaluations generally include questionnaires, surveys, checklists, interviews, documentation review and observations.

### WHO's M&E Toolkit

The M&E Toolkit developed by WHO adopts a similar M&E approach, although it is disease-specific *(2).* In particular, the WHO M&E Toolkit emphasizes the importance of comparable indicators across time and countries, data collection supported by a surveillance system, with a data dissemination plan.

### The Logical Framework Approach

The logical framework ('logframe') approach, while not explicitly elaborated in the UNDRR M&E framework, is an M&E management tool commonly adopted in development projects. Under the logframe approach, project strategy, objectives and outputs are clearly defined, with objectively verifiable indicators developed under each category, and they are all presented in a single matrix. Such an approach has been adopted in projects by several agencies in the United Nations family, including the United Nations Development Programme (UNDP) *(5)* and the United Nation Children's Fund (UNICEF).

### The Sphere Standards

The Sphere Standards are the most widely recognized principles and minimum standards for improving the quality of humanitarian operations and the accountability of the humanitarian sector. They comprise the Core Humanitarian Standard as well as standards in four technical areas, including health, water supply, sanitation and hygiene promotion; food security and nutrition; and shelter and settlement *(8)*. M&E is emphasized, with performance indicators listed for each of the nine commitments under the Core Humanitarian Standard. Moreover, “key indicators” is one of the main components of all the technical standards, covering various aspects of a humanitarian operation. For example, for an operation to control communicable diseases, relevant indicators include initiation of outbreak investigation within 24 hours of notification and case fatality rate maintained at 1% or lower in the case of cholera *(9)*. These indicators act not only as guidelines for designing health services during a disaster, but also for monitoring and evaluating the operations. In order to strengthen the role of M&E in humanitarian operations, the Sphere Monitoring and Evaluation guide has been published to elaborate on how the Sphere Standards could be used for M&E. M&E under Sphere emphasizes in particular monitoring of the context of the humanitarian operation, the activities and processes, and the impact of the operation on the affected population; and that there should be real-time evaluation, mid-term evaluation and final evaluation *(10)*.

## 4.15.4 Designing M&E studies for Health EDRM: the choices to be made

Although the existing frameworks provide some assistance to researchers in designing their own M&E studies, it is critical that the actual design must reflect the specific context of the study and fit the needs of the research. For any M&E study to serve its purpose, choices must be made in relation to a range of issues (such as approach, components, methods and process, and so on). This section elaborates on this aspect, in particular in regards to nature of the evaluation, evaluation framework, levels, data sources and study design.

### Nature of the evaluation

There are many different types of evaluation, depending on the objective of the study. These include formative and summative evaluations, which are further divided into various subtypes (Table 4.15.1):

**Table 4.15.1 Subtypes of formative and summative evaluations *(3)***

| Formative evaluation | Summative evaluation |
|---|---|
| Needs assessment | Outcome evaluations |
| Evaluative assessment | Impact evaluation |
| Structured conceptualization | Cost-effectiveness and cost-benefit analysis |
| Implementation evaluation | Secondary analysis |
| Process evaluation | Meta-analysis |

As discussed in Chapter 3.5 for research generally, M&E researchers need to be clear about their main objective and research question and select the most suitable type of evaluation accordingly. M&E studies in Health EDRM require appropriate and practical research methods for monitoring and evaluating the interventions implemented to strengthen DRR capacity. In general, more attention has been paid to impact evaluation than process monitoring.

### Evaluation framework

There are many evaluation frameworks available to Health EDRM researchers to help them plan systematic data collection, analysis and interpretation. After deciding on the nature of the evaluation, researchers could consider the study focus and draw up the most suitable evaluation framework. For example, an M&E study might focus on the outcome of interventions *(11)* or the cost and benefit of a DRR measure *(12)*. Moreover, researchers might wish to conduct a theory-driven study (see Chapter 4.10) to answer pre-defined questions *(13)* or to test hypotheses about what they expect to find. Case Study 4.15.1 provides an example of an M&E framework for disaster management at national level.

### Case Study 4.15.1
### South Africa Disaster Management M&E Framework *(14)*

South Africa is exposed to various weather hazards (such as drought and cyclones) and the country's extensive coastline means that there are potential marine and coastal threats (such as floods). Furthermore, people living in poor and ecologically fragile areas are faced with additional risks.

In light of severe disasters experienced in the 1990s, discussions and consultations at local, national and international levels led to the adoption of the Disaster Management Act in South Africa in 2002. The National Disaster Management Centre (NDMC) was established under the Act. To ensure the performance of disaster management-related policies and programmes, the South African Government issued the Disaster Management Monitoring and Evaluation Framework in 2014 to "provide a comprehensive and integrated strategic monitoring and evaluation direction to the entire Disaster and Fire services management to determine, on an on-going basis, how best to maximize the value of prevention, reduction, response and intervention". This Framework outlines:

- Key processes, mechanisms, tools, templates, strategies and methods for M&E;
- M&E architecture, system design and performance monitoring and evaluation plans;
- How evaluation findings will be used to enhance evidence-based decision making and accountability, and give feedback to policy development or implementation review mechanisms.

South Africa's Disaster Management Monitoring and Evaluation Framework requires that all evaluations should comprise three components: internal rapid assessment, long-term impact and multi-dimensional evaluation projects, and joint venture evaluation projects with strategic partners.

### Levels

Given the potential complexity of a programme, it is essential for researchers to decide which "levels" to focus on. The "level" might be at the activity or output level as opposed to the outcome or strategic level. It might also be at the organizational level, which may be international, national, inter-agency, community or the individual level (for example, patients or other beneficiaries). The choice of level affects the data sources and the study design. Multilevel M&E studies are possible.

### Data sources

Research methodologies for M&E studies in Health EDRM cover various components, including formulation of hypothesis and research questions, drawing up study design, recruiting subjects, designing research tools and data collection methods (what, when, how and by whom), choosing indicators, and data analysis and dissemination. Health EDRM researchers must be prepared to secure access to a wide range of data sources which could be fed into different components of the study. For example, different types of indicators require different categories of data sources, and whenever possible, there should be at least two sources of data for each indicator (primary and secondary sources) to allow triangulation of information *(3)*. In general, data sources can be grouped into three types:

- Documents: existing evaluations, progress reports and policy documents, media coverage;
- Qualitative data: in-depth interviews, focus groups, participants observation.
- Quantitative data: surveys, routine surveillance data, national or local registries, clinical samples.

M&E studies for Health EDRM must be considered in light of the unique setting of emergencies and disasters, which distinguishes them from conventional research. Randomized trials (Chapter 4.1) are the gold standard, in particular for evaluating clinical effectiveness, but cohort studies, case control studies, ecological studies and case series *(15)* might also be done (Table 4.15.2).

For disaster-related M&E research, quasi-experimental designs (QEDs) in which random assignment is not used, merit special attention. These have been increasingly used and encouraged in non-clinical and routine practice settings to test attribution of the intervention to the outcome change, including in public health *(16)*, and disaster and humanitarian settings *(17)*. Health research in disaster and humanitarian settings has used a range of research designs *(17–18)*. Random allocation, which is the essence of the randomized trial, may not be feasible in some disaster settings, but in using a QED, a balance must be achieved between the practicality of doing the study and its internal and external validity in order to reduce the risk of bias, especially selection bias *(16)*. One of the most important techniques to improve the validity of QEDs is to identify a comparison group that resembles the characteristics of the intervention group as closely as possible *(19)*. Some commonly used QEDs are discussed in Chapter 4.5; Case Study 4.15.3 is an example of quasi-experimental M&E study of a programme run by an international NGO among vulnerable population.

### Study design

In general, M&E studies in Health EDRM can take the form of quantitative study (Chapter 4.1), qualitative study (Chapter 4.12) and a concurrent or sequential mixed methods study (Chapter 4.13). Case Study 4.15.2 is an example of the use of a mixed methods M&E study in disaster management.

### Table 4.15.2 Experimental and quasi-experimental study designs in M&E for DRR Study design

| | Application to M&E studies in DRR context |
|---|---|
| **Randomized trial** | Gold standard for evaluating clinical effectiveness and demonstrating causality<br>May have restricted application in routine practice, due to its tightly controlled research environment<br>New or experimental intervention is provided to experimental group but not the control group<br>May be ethical issues involved in depriving the control group of the intervention, especially in a disaster setting |
| **Cohort study** | Comparison of the same group of people before and after the follow-up period<br>Some evidence in demonstrating causality<br>Limited application in some disaster setting due to difficulties in identifying the same group of people after a period of time |
| **Case control study** | Comparison between two groups of people which are categorized by their outcome<br>Efficiency for rare diseases or outcomes is low<br>Prone to selection bias because the selection of cases and controls is dependent on the criteria defined for the outcome |
| **Non-randomized comparative trial** | A form of QED without random allocation<br>Lower level of generalizability of results than randomized trials<br>Wider application in disaster setting |
| **Uncontrolled pre/post and interrupted time series study** | A form of QED with no control group<br>Minimizes ethical issues in disaster setting by providing interventions to all groups<br>Cannot demonstrate causality |
| **Cross-sectional study** | Practicable in many routine practice settings and for a population-based overview<br>Cannot demonstrate causality<br>Provides analysis at a specific time point only |

### Case Study 4.15.2
### Mixed methods quasi-experimental study of outcomes of a large-scale multilevel economic and food security intervention on HIV vulnerability in rural Malawi *(25)*

An impact evaluation study was conducted to assess the impact of an economic and food security intervention on health outcomes and HIV vulnerability in rural Malawi, implemented by CARE International Malawi from 2008 to 2010. This used a quasi-experimental non-equivalent control group design to compare 598 intervention participants with 301 participants in unrelated programmes in similar geographical areas. They were interviewed at baseline and again 18 and 36 months later.

The intervention was found to increase HIV testing and HIV case finding, decrease food insecurity, increase nutritional diversity and improve economic resilience. Most effects were sustained over the 36-month period.

The findings of this impact evaluation study allowed the NGO (CARE International) to identify areas for improvement in their programmes to create greater impact in reducing health risks in a vulnerable setting. The study also demonstrated the possibility of collaboration between an international NGO, local community and academia to conduct a controlled evaluation on locally tailored programmes in routine practice setting, providing scientific evidence on the impact of health-related development programmes.

Pre/post designs with non-equivalent control groups involves collecting data before an intervention and again after the intervention, and then a comparison of these two datasets, with the control group not being randomly assigned *(21)*. Interrupted time series involves multiple observation points over a period of time before and after the intervention with the same group of people *(22)*. A stepped-wedge design generally involves a staggered introduction of the intervention for different groups, and could involve serial cross-sectional data collection, either by site or by a cohort of individuals over a period of time and might include randomization to determine when the intervention is introduced (Chapter 4.3) *(23)*. Some advantages of these designs might include lower cost and greater flexibility, and that they avert the need for a control group of people who will not be provided with the intervention *(16)*. However, measures must be taken to enhance the validity of these studies in the absence of random assignment in order to ensure that biases have been sufficiently minimized to demonstrate attribution and techniques such as propensity score matching and the regression discontinuity design might be used. These are discussed in Chapter 4.5 and the Handbook on Impact Evaluation published by the World Bank *(24)*.

### Case Study 4.15.3
### Heat wave plan for England *(20)*

Heatwaves are considered a public health threat in the United Kingdom, especially after the 2003 European heatwave which caused 2000 deaths in the United Kingdom. As a result, the Heatwave plan for England has been published and reviewed annually since 2004, with the latest version published in 2018. The Policy Innovation and Evaluation Research Unit of the United Kingdom's National Institute for Health Research was tasked by the Department of Health and Public Health England to conduct an independent evaluation of the plan (2015 version). A mixed methods study was adopted, involving time series analysis, case studies, and quantitative surveys.

**Study design: mixed methods evaluation:**

1. Time-series analysis of health data to examine the association between temperature and mortality/morbidity before and after the introduction of the Heatwave plan;
2. Detailed case studies focusing on implementation of the plan;
3. National survey to understand knowledge, attitudes and behaviour of the general population during heatwaves.

**Research questions:**

1. "Has the introduction of the plan in 2004 had any effect on mortality?"
2. "How well is the plan being implemented locally, including at the 'frontline' of health and care services?"
3. "Is the general population aware of the risks of heat and overheating buildings, do they change their behaviour as a result of hearing heat alerts or advice, and do they take any actions to prevent potential effects of hot weather?"

Although quasi-experimental studies have been conducted in disaster management, the relevant requirements might still be unrealistic for M&E studies in some contexts, such as during the impact stage of a large-scale disaster in a vulnerable State or after a disaster when there is an absence of baseline data. Under such circumstances, researchers might need to use other non-experimental designs, such as participatory monitoring and evaluation, where stakeholders at various levels are engaged to deliberate the relevant process, results or policy of an intervention *(26)*, or ethnographic methodologies *(27)*. Case Study 4.15.4 is an example of participatory action research in a disaster management context.

**Case Study 4.15.4**
**Participatory action research: The World Trade Center evacuation study *(26)***

Participatory action research (PAR) was employed to identify the individual, organizational and structural factors that affected evacuation from the World Trade Center (WTC) Towers 1 and 2 on 11 September 2001.

1767 people who worked in one of the towers at the time of the terrorist attack completed the study questionnaire and 11 participated in the PAR teams, which also included professional investigators, experts and specialists. The study investigated the time taken to initiate and complete the evacuation and the incidence of injury.

Quantitative data were collected through questionnaires completed by evacuees. Qualitative data were collected through structured deliberations by the PAR teams, with participation by researchers and consultants.

The PAR teams identified the key risk factors associated with the three study outcomes and prepared 83 recommendations that addressed the risk factors. More than half of the recommendations were aimed at the organizational level, 26% at the structural level, and 23% at the individual level.

This study attempted to illustrate the effectiveness of the PAR methodology for identifying risk-reduction interventions, emergency preparedness and response strategies in disaster research.

### 4.15.5 M&E studies in Heath EDRM: practical examples of challenges

Health EDRM research often takes place in unconventional settings, which calls for innovative and practical methodologies that are nonetheless sufficiently robust. Some of the critiques on impact evaluation regarding humanitarian assistance are also applicable to DRR. For example, Puri and colleagues *(28)* considered that impact evaluation in such unorthodox settings faces methodological, practical, and ethical challenges. In regard to methodology, there are concerns about the potential to compromise the validity of the findings, in particular as to whether the outcome can be causally attributed to the intervention if randomization is not used to minimize biases between the intervention and control groups *(29)*. In regard to ethical challenges, the foremost concern is the need to have a control group, which could mean that some individuals may be deprived of the experimental interventions that might actually be life-saving through its effects on reducing disaster risks.

Apart from the many complexities that a disaster setting presents to Health EDRM researchers (for example, the wide range of possible interventions, different natures and scales of disasters, and potentially large number of collaborators and funders involved), one distinct practical difficulty for M&E studies is the conceptual challenge of demonstrating the impact of an intervention that had prevented something from happening or reduced the health risks. Outcomes related to knowledge, attitudes and behaviours, and proxy indicators are therefore commonly adopted *(6)*. Furthermore, the availability and quality of data is a long-standing issue for all DDR researchers, including those doing M&E studies. The data readiness review conducted under the Sendai Framework revealed that data quality remains an issue and data accessibility is also highly limited in many low- and middle-income countries *(30)*. This makes it difficult to select reliable indicators *(31)* and the relevance of indicators is critical to the success of any M&E study. The seven targets and 38 indicators under the Sendai Framework *(4)* have become the globally recognized foundation for researchers to develop indicators suitable to their needs. With health explicitly recognized and mainstreamed in the Sendai Framework, this provides a useful reference point for Health EDRM researchers developing indicators for their M&E studies.

An increasing number of M&E studies are moving towards multi-country or multi-agency settings, given the encouragement for stronger multidisciplinary and cross-country collaboration in DRR. M&E studies are particularly important for DRR initiatives involving multiple actors, but these studies have special challenges. For instance, different actors may have different priorities (Chapter 2.7) and study direction will need to be relevant to all partners. Moreover, all parties need to adopt the same approach if they are to generate comparable data. Differences in the data availability and data quality between actors are often another concern. One way to ensure relevance is to set up standardized key M&E questions and indicators, while allowing different partners to develop their own supporting M&E questions and sub-indicators *(32)*.

### 4.15.6 Conclusions

M&E provides evidence to help inform understanding of the effectiveness of DRR interventions. Robust and practical M&E studies are essential if Health EDRM initiatives are to be effective and sustainable. This chapter has described the important role of M&E research, existing M&E frameworks related to health and DRR programmes, and described some of the research designs that can be used for such studies and related challenges. While experimental and controlled studies remain the mainstream research methodologies most widely recognized in academia, researchers may need to consider how they can develop studies that are feasible in emergency and disaster settings without compromising strength in demonstrating causality. Researchers need to have the courage and expertise to develop and continuously enhance research methodologies that fit the needs of routine practice if the findings of their M&E studies are to meaningfully guide the allocation of limited resources in Health EDRM.

## 4.15.7 Key messages

- **M&E studies can be used to demonstrate the effectiveness of Health EDRM interventions and be instrumental in providing evidence and justifications for sustainable resource allocation.**
- **The M&E framework chosen by a researcher will determine the study focus during data collection, analysis and interpretation of its findings.**
- **Randomized trials might not be practical for some Health EDRM M&E studies and quasi-experimental designs are increasingly used.**
- **In conducting M&E studies with quasi-experimental design, measures must be taken to minimize bias and ensure the internal and external validity of the study, and findings must be interpreted in light of the specific context of the study.**
- **The poor availability of high-quality data and the selection of indicators are two major challenges for M&E studies in Health EDRM.**

## 4.15.8 Further reading

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# Special topics to demonstrate research processes and benefits

## 5.0

# 5.1 Disaster mental health research

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## 5.1.1 Learning objectives

To understand the importance of the following for mental health research relevant to health emergency and disaster risk management (Health EDRM):

1. Mental health consequences of disasters;
2. Research methods appropriate for assessing mental health;
3. The importance of partnerships to support mental health research in disaster settings;
4. The role of culture in defining the experience and expression of distress.

## 5.1.2 Introduction

The accelerating risk of complex emergencies arising from climate change and human conflict will have major implications for mental health, making this an important aspect of Health EDRM. Exposure to trauma during disasters and conflict, together with the cascading effects of bereavement, forced displacement, injury and resource loss has the potential to cause long-term psychological distress *(1–3)*. Urbanization often compounds disaster risk, particularly in low-resource areas, where population density presents significant threats to health, social capital and community resilience in humanitarian emergencies *(4–5)*.

Despite high levels of need, mental health is a relatively neglected area in Health EDRM, with little focus on services funding, human resources or research in the field *(6–7)*. Consequently, there is tremendous opportunity to improve disaster mental health risk reduction through rigorous research and informed policy. This chapter presents an overview of methods applied in recent research and important considerations for developing rigorous protocols in mental health assessment.

### 5.1.3 Psychological responses to trauma

In the face of crisis, people naturally react with fear, horror, sadness and grief *(8)*. For most people, this early trauma response resolves over time *(9–10)*; and the provision of psychosocial and community support during the early stages of recovery will likely reduce the incidence of more severe psychological issues *(11–13)*. However, in a sizeable minority of cases, psychological distress remains high for months and even years *(1, 14)*. In fact, it is typical for PTSD and other forms of psychological distress to develop some time after the acute crisis. Despite the definition of mental health as a second-wave issue in disasters, its later timing does not lessen the severity of need *(15)*. However, the secondary surge in demand for health care and other forms of psychosocial support often occurs when attention has shifted away from the disaster, and funding for health services has already been channelled into the treatment of injuries, infectious diseases and pre-existing chronic conditions. Addressing mental health in the aftermath of disasters therefore requires careful long-term planning and substantial knowledge of the pattern of response across affected populations. These issues are similarly important for research design: early assessment will illustrate elevated patterns of distress across the population, which is likely to diminish over time for the vast majority. Thus, targeted and well-timed research is required to reliably demonstrate the mental health impacts of disasters.

Exposure to trauma has potential to induce a range of psychological and neuropsychiatric disorders. The rates of psychological disorders following disasters vary widely *(16)*, but consistent evidence indicates that up to one third of survivors develop PTSD, and one quarter report depression *(11)*. Substance use disorders are less likely to be caused by trauma, but may be exacerbated *(17)*. Less attention has been paid to the rates of anger disorders, suicide, psychosis, and traumatic brain injury following disasters *(18–20)*. Key risk factors for the cause or maintenance of psychological distress among survivors include severity of trauma exposure, female gender, pre-existing psychological conditions and the presence of ongoing chronic stressors in the post-disaster environment *(11, 18)*. Trauma related to interpersonal violence and conflict leads to poorer mental health outcomes than natural or technological disasters *(16)*. Research in this field has largely focused on the effects of exposure to earthquakes *(21)*, bushfires *(1)*, windstorms *(22)*, floods *(23)*, terrorism *(24)*, and war *(25)*. As climate change shapes the patterns of disaster risk and conflict globally, a greater focus on the consequences of extreme temperatures, water insecurity, trade disputes, civil unrest, and the compounding and interacting effects of pre-existing vulnerabilities will be needed.

### 5.1.4 Assessing mental health in disaster-affected areas

Research methodologies relevant to the assessment of mental health after disasters have expanded to include increasingly innovative techniques. These approaches can be applied to examine the full spectrum of psychological response, including examinations of resilience, subclinical mental health issues, acute reactions and long-term psychological distress and dysfunction. Research methods are discussed in greater detail in Section 4, but the following examples highlight ways in which quantitative and qualitative methods can be applied to the investigation of mental health issues.

### 5.1.5 Quantitative research

Quantitative research designs seek to answer questions related to the prevalence of mental health problems, their correlates, symptom course, and effects of intervention. The vast majority of disaster mental health studies have used cross-sectional survey designs, employed to report the rate of mental health issues evident in affected populations; however, a growing number of longitudinal and cohort studies have shed light on the trajectory of psychological response to disasters and the risk and protective factors associated with outcomes (Chapter 4.4) *(13, 26-27)*. For example, the English National Study of Flooding and Health, the Queensland Flood Study in Australia, and Project Ice Storm in Canada, have established important findings on the long-term consequences of disaster exposure across the lifespan, including the longitudinal effects of prenatal disaster stress *(28-30)*. Cohort studies are less common in conflict and post-conflict settings, although the Longitudinal Study of War-Affected Youth has illustrated the specific risk and protective factors associated with mental health trajectories for youth in Sierra Leone *(9)*. More recently, a range of innovative analytic techniques has emerged in the field. For example, various statistical methods have been employed in disaster mental health research (see also Chapters 4.2 and 4.4), including the use of time series data analysis to assess psychiatric hospital admissions associated with hot temperatures *(31-32)*, multilevel longitudinal analysis to determine the mental health effects of group involvement following bushfires *(26)*, latent class analyses to assess the psychological factors associated with urban evacuation preparedness *(33)*, and geospatial patterning of vulnerabilities after hurricanes *(34)*.

### 5.1.6 Disaster mental health services research

Understanding the likely and locally presenting mental health impacts of disasters is crucial to the design of strategies to reduce mental health risks and inform the delivery of effective support measures and services that optimally facilitate recovery *(35)*. As our scientific knowledge base regarding the mental health consequences of disasters consolidates, disaster mental health service research can play a vital role in furthering its effective translation into quality disaster mental health response and support services *(36–37)*. In this context, disaster mental health service research has been instrumental in monitoring ongoing mental health care needs, service demand and equitable service access of disaster-affected populations *(38)*, whilst capturing important intervention outcomes *(39-40)* and key lessons to enhance the quality and organization of future disaster responses *(41)*. Evidence-based elements for effective disaster mental health response include: the effective coordination of multiple disaster response agencies and support services across varying sectors and jurisdictions *(42)*; the integration of enhanced disaster mental health services within existing support structures, such as primary care *(43)*; facilitation of ready access to care *(44-45)* and creation of pathways between different levels of care *(46)*; targeted capacity building for disaster responders in evidence-informed and scalable interventions *(47)*; as well as timely and transparent communication among all involved stakeholders and the wider community. Importantly, data from additional sectors, including schools (48-49), non-profit organizations *(50)*, and community groups *(51-52)* will augment services data to highlight the short- and long-term community needs and treatment outcomes. However, not all sectors or settings will have capacity for data collection and record keeping, particularly in the context of extensive damage to infrastructure and loss of human resources (Chapter 2.4). In such cases, it may be more appropriate to implement alternative techniques of inquiry, such as mixed methods research (Chapter 4.13).

The integration of health service research and evaluation into disaster preparedness and response is essential to develop the evidence base for effective interventions and critical to ensuring that the supports put in place are well-coordinated and are reaching those most affected. While each disaster context is unique, and there are psychosocial disaster response guidelines that can be tailored to local circumstances, comparative disaster mental health services research is now starting to elevate our understanding beyond the locally unique and allow the incorporation of what works well both within and across contexts *(42, 53-54)*, thereby establishing the key elements for more effective disaster mental health responses and proactive risk reduction efforts in future.

### 5.1.7 Qualitative research

Qualitative research presents an opportunity to gather in-depth or exploratory data on topics not always assessable via quantitative methods. As discussed in Chapter 4.12, qualitative research may be used to investigate sensitive or taboo topics related to mental health and to broaden inclusivity to populations not often included in the evidence base *(55)*. Often characterized by the use of smaller, purposive samples and collection of narrative data, qualitative research enables a deep exploration of meaning and relationships. Although a variety of approaches and analytic techniques are available, qualitative methods are usually focused on describing, exploring and interpreting the participants' frame of reference and worldview *(56-57)*. These methods are particularly relevant to disaster research. Recent applications have included the rapid assessment of needs following exposure to trauma *(58-59)*, social network analysis in communities preparing for hazards *(60)*, and the exploration of mental health symptoms among cultural groups rarely represented in the literature *(55, 61–62)*.

## 5.1.8 Participatory action research

Participatory action research (PAR) engages study participants in active co-researcher roles to broaden the scope of research with novel perspectives, disrupt dominant paradigms, and champion inclusive approaches (see examples in Chapters 3.1 and 4.15) *(63)*. Working within a co-design framework fosters ownership of the process and findings within the community, and supports innovative, meaningful outcomes. By disrupting the power imbalance between researcher and participant, PAR fosters a sense of agency among community members. PAR with children and adolescents affected by disasters has sought to dispel the perception of children as passive and vulnerable, instead recognizing their right to contribute to the decisions affecting their lives *(64)*. Similarly, PAR has been used to develop more inclusive policies and practices for marginalized groups and minorities across a range of disaster settings *(65–66)*. An example of PAR for mental health research is given in Case Study 5.1.1.

### Case Study 5.1.1
### Working with communities to assess the effects of disasters *(67)*

A participatory approach can add value to disaster research in many ways, including unique insights from community members and shared ownership of outcomes – but there are also many ways it can go wrong. The post disaster environment is chaotic, communication and social networks are often fractured, and the social bonding that can occur in response to a shared disaster experience can also deteriorate over time into disagreements and conflict. The ethical and academic implications for researchers are fraught, and need to be managed with care.

The Beyond Bushfires: Community Resilience and Recovery study was conducted in Victoria, Australia following the February 2009 bushfires, commonly referred to as the 'Black Saturday' bushfires because the worst of the fires occurred on Saturday 7 February *(68)*. The six-year study involved a cross-disciplinary team of academic investigators who valued cross-sectoral input and so invited a range of government, emergency, and health sector partners to attend all investigator/partner study meetings for shared decision making. Community expertise was also considered essential, and the lead investigators from the University of Melbourne began with a series of community visits to seek advice on the study methodology, recruitment locations and contextual differences. Twenty-five rural communities accepted the invitation to become study sites representing high, medium and low impact communities. It very quickly became clear to the investigators that there were so many diverse and sometimes conflicting views within and across those communities that it would be unhelpful and offensive to simply have a few community spokespersons join the investigator/partner study meetings held in the city to contribute to decision making. Instead, the lead investigators committed to ongoing community visits throughout the study, calling and visiting people for chats, attending local meetings and presenting emerging findings at local seminars. They maintained connections with a wide range of individual and organizational contacts and channelled the feedback and insights provided to the investigator/partner meetings to ensure community influence on study decision making occurred at all stages of the research process and that it was sufficiently nuanced to reflect the complexity of individual and community level experiences. This approach resulted in continuing adjustments to the study, including the study name, adjustment to the recruitment boundaries, the sampling strategy, communication methods, survey questions, focus of data analyses, interpretation of findings, study output and dissemination strategies. These continual responses to feedback demonstrated the investigator commitment to a participatory approach and greatly enhanced the relevance and impact of the findings *(67)*. As one community member noted about the Beyond Bushfires study "Most importantly, it has provided a safe, supportive environment for us to explore the lived experience of bushfire recovery" *(67)*. This shows the value of a participatory approach for those involved but also the potential for harm if the participatory efforts are merely tokenistic. A participatory approach requires genuine commitment on the part of the investigators to adapt to the realities of a post-disaster environment. If that can be achieved, the research quality and the study impacts are likely to exceed a traditional approach to research.

## 5.1.9 Considerations for working with disaster-affected populations

**Conducting research with traumatized populations**

Mental health research often requires engaging with people who are actively experiencing distress or are required to remember difficult times. Accordingly, participating in research has the potential to exacerbate stress, irritation or fatigue, but is still valued by participants and, if carefully managed, is unlikely to contribute to further trauma *(69)*. Investigators working with disaster survivors must be mindful of the way they conduct their research to ensure that participants are protected from distressing or ethically compromised protocols. Possible means to address this concern might include:

- ensuring comprehensive training is provided for the research team, with a focus on research ethics, confidentiality, sensitivity, risk assessment and building rapport;
- developing a referral network prior to the commencement of research, so that higher risk cases may be referred to specialist care;
- engaging community stakeholders to guide research design and data collection.
- speaking with participants about their social support networks and ways that they can access further information and assistance.

**Mental health stigma**

The stigma associated with mental illness calls for thoughtful planning for conducting research and disseminating findings. The use of scientific evidence presents an important opportunity to reduce stigma around psychological responses to trauma, if done well. Discussions of mental illness that inadvertently reinforce community concerns (such as associations between psychological symptoms and weakness or danger) can reinforce stigma *(70)*. Challenging stereotypes through positive messages of change, associating help-seeking with strength, and normalizing trauma reactions has significant potential to mitigate stigma among survivors *(71)* and first responders *(72)*.

**Cultural expressions of distress**

Culture plays an important role in the expression of distress. Cultural expectations and socialization processes shape the norms for psychological and behavioural phenomena, which are dynamic and vary with time (for further detail, see Case Study 5.1.2). Using qualitative research to explore common descriptions of stress, mood and behaviour change may illuminate meaningful symptom clusters and idioms of distress *(73-74)*. In addition, adoption of a 'cultural lens' is required to effectively interpret the influence of gender, family composition, coping, social determinants, and developmental stages in the expression and experience of psychological distress *(75)*. Using culturally and (where suitable) developmentally appropriate terms to describe psychological expressions will significantly improve the validity of the research. Without careful consideration of culture, our research paradigms, sampling strategies, methods of data collection and interpretation of findings will be significantly flawed *(75)*.

### Case Study 5.1.2
### Expressions of distress among disaster-affected adolescents in China and Nepal *(74)*

China and Nepal have recently experienced devastating earthquakes. Both nations have large adolescent populations, for whom traumatic stress has potential for significant effects on mental and physical health, development and education *(59)*. To address these issues, it is vital that we understand the specific experiences of young people affected by disasters.

The Study on Adolescent Resilience after Disasters sought to investigate the range of expressions of psychological distress and any behavioural changes arising from exposure to natural disasters *(74)*. Ethnographic research in Nepal has illustrated a multifaceted model of psychological trauma, with particular emphasis on interpersonal relationships, social identity and loss *(61, 76)*. In China, mental health is conceptualized within a holistic systems approach with greater integration of the concepts of mind and body *(77)*. However, diversity in the conceptualizations of psychological distress in both countries, and a lack of attention to child and adolescent experiences warranted in-depth assessment *(74)*.

Key informant interviews and focus group discussions were conducted with adolescents, caregivers, teachers and experts in disaster-affected districts of Yunnan Province, China (n=79), and Kathmandu Valley, Nepal (n=62). A thematic analysis revealed that key indicators of distress emerged across four domains: anxiety and stress, mood difficulties, somatic complaints, and changes in behaviour. Young people frequently described fear of the earthquake recurring, anxiety triggered by trauma reminders, nightmares and hypervigilance. An adolescent participant from Nepal said "They say the sound of people shouting when the houses collapsed haunts them... I have not seen, but my friends say they are afraid to go anywhere in the dark, the sound of people shouting is heard" *(74)*. The magnitude of the Nepal earthquakes was associated with a sense of existential worry among adolescents who were forced to examine their future in light of new and worsened hardships. Concurrently, post-traumatic growth and strengthened connections between adolescents and their families were described in both settings. A number of participants described a sense of coping, mastery and self-efficacy arising from their experience *(74)*.

Many of the symptoms described by adolescents and their families reflect diagnostic criteria for PTSD, depression and anxiety, perhaps due to an increasingly globalized communication of mental health *(74)*. However, the nuanced descriptions of psychological distress highlight a significant need for psychological and community services that promote evidence-based interventions tailored to culturally specific understandings of mental health and the unique capabilities of adolescents.

## 5.1.10 Establishing research partnerships

Identifying and engaging local partners is crucial to conducting field-based research. International studies should always be conducted in partnership with local organizations, service providers, government advisors, and/or community representatives. Such partnerships are also advisable when working in the researcher's home setting, where there may be opportunities to establish working relationships prior to the onset of a disaster. Local research partners play a vital role at multiple levels of the research process, from advising on study feasibility and acceptability, developing methodology, recruitment and sampling, obtaining ethics approvals, data collection, managing risk, interpreting results and disseminating findings within and beyond the community. Whether working in high-, middle- or low-income nations, building capacity in the mental health workforce (across both clinical and non-clinical settings) should be incorporated in the planning.

Successful partnerships are dependent on open communication, inquisitiveness, trust, humility and follow-through on decisions *(78)*. Regular team meetings and agreements regarding data ownership, respective roles in data collection and paper authorship facilitate this process *(79)*. Furthermore, an understanding of the political, economic, social, environmental and technical realities that shape interactions will foster stronger relationships *(80)*. Research partnerships are most successful when teams agree on a strong research plan, have respect for each other's capacities, engage in transparent and effective communication, clearly delegate roles and responsibilities, and develop a shared vision for the project *(79)*. Without collaboration, research conducted in disaster-affected settings is at risk of duplicating processes, drawing false conclusions, or failing to have a meaningful impact on policy and practice.

## 5.1.11 Dissemination and impact

The uptake of results and sustainability of new mental health initiatives are dependent upon the early engagement of partners and community members. An early process of joint decision making aiming to achieve multiple research project outcomes to meet the needs of all partners will support community engagement and research validity. In addition, it is important to foster progressive development of a knowledge translation plan to ensure wide dissemination of the findings and outputs tailored to different audiences and contexts. Scientific manuscripts and academic products can be complemented by community seminars and workshops, promotion through social and traditional media, and creating opportunities for partners to present findings in community forums. As funding bodies and individual donors become more interested in the efficiency of resources, providing reliable evidence on the level of need and effectiveness of humanitarian interventions will become increasingly valuable.

## 5.1.12 Conclusions

Mental health research plays a critical role in determining the health needs, trajectories of adjustment and treatment outcomes for disaster-affected populations. It has an important part to play in Health EDRM. Both clinical and non-clinical supportive services in the acute recovery phase have potential to support population-level improvements for adult and child mental health *(12)*. Rigorous research that pays careful attention to inclusive sampling, ethical processes, social determinants of risk and cultural considerations has the potential to expand the evidence base and highlight important areas for service development. Collaborative partnerships are vital: where possible, mental health researchers should seek to work in partnership with other agencies and local community members to guide the research and build capacity in the settings in which they work. The tremendous potential for research to inform and prevent mental health difficulties and deliver timely, evidence-based intervention will support the long-term resilience of disaster-affected communities.

## 5.1.13 Key messages

- **Rigorous mental health research is needed to determine the specific needs of disaster-affected populations and effectiveness of interventions in the months following a disaster.**
- **Consideration of the timeframe for psychological adjustment, sample characteristics and cultural expressions of distress will inform the research design.**
- **Partnerships with local community stakeholders, agencies and research collaborators are vital for valid research, capacity building and long-term uptake of results in Health EDRM.**

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# 5.2

# Crowdsourcing to gather data

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## 5.2.1 Learning objectives

To understand the fundamentals of crowdsourcing and its relevance to Health EDRM, including:

1. What crowdsourcing is;
2. How crowdsourcing differs from related terms;
3. Strengths and limitations of crowdsourcing;
4. Things to consider when designing a study that would use crowdsourcing to gather data.

## 5.2.2 What is crowdsourcing?

Crowdsourcing, which is a method to harness the knowledge, creativity, or sheer manpower of a large number of people at once, has existed as a concept for hundreds of years, although the term itself was only coined a decade ago *(1–5)*. The term ‘crowdsourcing’ first emerged in a *Wired Magazine* article, and was described as a method of outsourcing tasks to an undefined, and generally large number of people using an open call. A commonly cited, classic example demonstrates the power of crowd wisdom in guessing the weight of an ox at a fair (Case Study 5.2.1). In the past decade, uses of crowdsourcing in research and practice have increased greatly, although many authors still feel the method is underutilized and underexploited *(6–9)*. This chapter explores the potential of crowdsourcing to help with research relevant to Health EDRM.

### Case Study 5.2.1
### A historical example of crowdsourcing

In 1907, Francis Galton wrote an article in *Nature* describing an experiment he conducted in Plymouth, West of England, where a crowd was invited to judge the weight of an ox. Some 787 votes were collected, and the average of these was incredibly close to the actual weight of the ox – within 1% of the real value *(10)*. Indeed, Buecheler et al. argue that individuals are biased towards the correct answer and that, because of this, if one million people contributed to solving a problem using crowdsourcing there would be a 97.7% likelihood that the crowd would arrive at the correct answer *(11)*.

Although technology is not a requirement for crowdsourcing, advances in technology have facilitated the impact and feasibility of crowdsourcing as a method. For example, at least 70% of the world's population has access to a mobile phone *(12)*. These devices can collect photo, video, acoustic, gyroscopic (measuring orientation), accelerometric (measuring acceleration), and proximal information, and can also be paired with external sensors such as air pollution sensors, or a wearable device such as a "smart watch" that will collect both gyroscopic and accelerometric information to track fitness by combining speed and location *(13)*. Mobile phones can also produce geographic information system (GIS) data (see Chapter 4.8), which are especially valuable in emergency situations *(14)*. Advances in artificial intelligence (AI) and machine learning algorithms provide new ways of processing the large amounts of data obtained through crowdsourcing (for example through receipt of many submissions, or through wearable sensors or mobile phone data).

Crowdsourcing can provide answers to questions that may be impossible or not feasible to answer otherwise by considerably lowering operational and data collection costs, while exponentially increasing sample size, and enabling researchers to receive data in real time *(14–20)*. As research in disaster situations faces time, funding, and logistical constraints – including staff and equipment – crowdsourcing may offer a desirable alternative or complement to traditional research methods *(8, 15, 21–28)*. However, as the crowd is often self-selected, there are concerns about the generalizability of samples. In cases where the information requested is sensitive, security and data protection issues also need to be considered. Efforts need to be made to design studies that can combat false submissions (from malicious contributors, for example, or if on a platform such as Amazon Mechanical Turk, malicious workers). Finally, concerns about the representativeness of the sample when crowdsourcing studies have very few contributors doing most of the 'work' or access to technology, age, and other demographic factors may affect who is able to contribute *(14, 29)*.

There are several different models of crowdsourcing, as well as similar and overlapping terms. While there is disagreement on the scope, categories, and types of models of crowdsourcing *(4)*, four basic and comprehensive categories emerge: crowd processing, crowd rating, crowd solving and crowd creation. These are outlined below.

### Crowd processing

Crowd processing is the use of large numbers of people to process information independently, which become partially aggregated for quality assurance. This is described as a 'divide and conquer' approach. Examples of these include ReCAPTCHA, GalaxyZoo and the BioGames example provided later in this chapter.

### Crowd rating

Crowd rating is the use of large numbers of people to vote or provide their opinion (such as TripAdvisor or Hollywood Stock Exchange).

### Crowd solving

Crowd solving is the use of a large numbers of people to solve a problem, where the best submission is the 'winner.' Example of this are FoldIt, Crowdmed and Innocentive.

### Crowd creation

Crowd creation *(30)* is the use of large numbers of people to co-create, such as Threadless.

In addition to the above four categories, crowdsourcing needs to involve a clear call for submissions or tasks, which can be voluntary or remunerated, and is usually conducted using some technology to enable low-cost and speedier data transmission. The crowd can be formed of laypersons or experts, but who the study is targeting should be decided for each problem. Responses may be aggregated or could be compared against each other in competition form. A comprehensive description of types of crowdsourcing can be found elsewhere *(4)* and some of the relevant terminology is shown in Table 5.2.1.

**Table 5.2.1 Terms related to crowdsourcing and their definitions**

| Term | Definition |
|---|---|
| **Participatory epidemiology** | Using participatory methods in epidemiology, which could range from designing the study to participatory methods in data collection (the latter would likely be in line with crowdsourcing) *(31)*. |
| **Wisdom of the crowd (that is, collective intelligence)** | A phrase coined by Surowiecki *(32)*, describing a form of crowdsourcing that relies on having an intelligent crowd and follows four 'rules' to ensure crowd intelligence: diversity, aggregation, decentralization and independence. Not all crowdsourcing requires a wise crowd, but all 'wisdom of the crowd' activities are crowdsourcing. |
| **Citizen science** | Non-professionals conducting science-related activities *(33)*. While crowdsourcing refers to *how* the activity is conducted, citizen science refers to *who* is doing it, and *what* they are doing. Often, crowdsourcing and citizen science are performed in tandem. |
| **Health 2.0** | The use of Web 2.0 technologies to actively participate in one's health *(33)*. These could facilitate crowdsourcing (for example, through using wearable sensors to transmit data en masse), but may also be used individually for personal tracking. |
| **Open-sourcing or peer production** | Open sourcing is the development of data or materials that will become freely available, where there is often no clear 'call' to work. In crowdsourcing, an organization would initiate the work *(15)*. |
| **Outsourcing** | Crowdsourcing can be defined as a niche form of outsourcing *(2)*. However, unlike outsourcing more generally, there is no contract for crowdsourced work *(9)*. |

### 5.2.3 Use of crowdsourcing in health research and emergency situations

Although, as noted above, some have argued that crowdsourcing has not been used to its full potential *(5–9)*, there are several notable examples that show the power of this innovation.

For instance, BioGames, uses the power of large crowds and gamification to analyse malaria smears. An online game, accessible via an Android device or computer, was created. The game has players 'kill' malaria parasites on blood smears using a syringe and collect healthy cells, after a short tutorial. Gamers have been able to reach 99% accuracy *(34–35)*. An educational version of this game was also created, which used a diagnostician to provide feedback to the gamers. In this version, gamers were more easily able to identify infected cells than healthy ones. The authors suggest that in future, gamers or machine-learning algorithms could pre-screen positive or negative marked cells and send questionable ones to experts for diagnosis *(36)*.

The OpenZika Project called for people around the world to volunteer their spare computing power, helping the project run simulations of potential drug candidates for Zika *(37)*. By using computing power from volunteers around the world, this project ran 92 000 simulations. All data from this project is open access.

Crowdsourcing is often used for disease surveillance in emergency settings (Chapter 2.2). Several open-source participatory epidemiology programmes exist, including Frontline SMS and Ushahidi. Participatory epidemiology is the use of people to gain epidemiological data (and is, by definition, a form of crowdsourcing). Frontline SMS enables users to request needs, such as supplies and logistical challenges, via SMS. It has been used in the Republic of Malawi, Republic of Burundi, Bangladesh, and the Republic of Honduras. Ushahidi creates individual reports using web, SMS, and email, which are classified, translated and geotagged *(19–20, 38)*. Ushahidi was initially created to respond to election violence in Kenya, but has since been used in many countries around the world, and most famously, to respond to the aftermath of the Haitian earthquake, as described in Case Study 5.2.2.

**Case Study 5.2.2**
**The use of Ushahidi in Haiti**

In January 2010, a 7.0 magnitude earthquake struck Haiti causing mass destruction in populous areas. Ushahidi, an open-source crowdsourcing platform, was deployed within four days of the earthquake. It provided vital information to responders. Ushahidi opened an SMS service for Haitians to text their needs, including food, aid, and medical needs, to a free SMS number, which was visualized geographically using cell phone tower triangulation, Google Earth, and Google Street Maps. Reports were triaged, and volunteers were able to text back. Translation was done by volunteers. Over 25 000 text messages were received. Of these, almost 3 600 were actioned, most relating to needs for vital services *(20, 39)*.

Other recent examples of Ushahidi's use include reporting violence after the US election, sharing geolocation information for flood help in Chennai, reporting earthquake damage in Puebla, Mexico using geolocation and photos, and tracking logistics after a terrorist attack *(38–41)*

In humanitarian or disaster relief settings, perhaps the most common use of crowdsourcing is for mapping. Ushahidi, Frontline SMS, Missing Maps and Humanitarian Open Street Maps either create maps for disaster preparedness or are able to work with crowdsourced maps (such as Open Street Maps) to enhance mapping capabilities, and to use these in coordinating a response. In many countries prone to disasters, there may be a lack of accurate maps containing basic geographic information, so efforts to create accurate maps in advance can be essential to responding effectively (see Case Study 5.2.3) *(38, 41)*.

### Case Study 5.2.3
### Open Cities for disaster risk management in Nepal

In addition to being one of the countries most exposed to natural hazards, the majority of houses in Nepal's capital, Kathmandu, do not meet minimum requirements for earthquake safety. As a proactive approach, local stakeholders in Nepal began using Open Street Map in 2012 to collect exposure data and map schools and health facilities. In Kathmandu 2256 schools and 350 health facilities were mapped. In April and May 2015, two high magnitude earthquakes hit Nepal. While these halted the initial Open Cities project, the existing information was crucial in informing humanitarian responders and supporting recovery efforts *(42)*.

MoBuzz, a participatory epidemiology application to combat dengue in Sri Lanka, is a good example of a multi-component crowdsourcing application. It uses predictive surveillance, civic engagement and health communication to reduce the exposure of the Sri Lanka population to dengue. The application uses predictive technology and machine learning algorithms to determine weather, vector and human data and produce hotspot maps for public and health officials. Civilians are engaged to report breeding sites, symptoms and bites, which are in turn reflected on the hotspot map. Finally, this information is communicated widely to the public and health officials *(43)*. Similar campaigns to this, or that reported more recently by Bartumeus and colleagues *(44)*, could be employed in emergency situations using this as a model.

Geographical sciences have also used crowdsourcing and these applications could be easily adapted for use in Health EDRM. One application, Sapelli, has successfully used citizen science and crowdsourcing to map poaching in sub-Saharan Africa through icon interfaces on a smartphone application *(45–46)*. The Sapelli application is icon-based and suitable for use by people with low literacy. It, or a similar application called CyberTracker *(47)*, and their underlying participatory methodology, could be tailored to report a variety of relevant health outcomes, such as disease monitoring, water and sanitation hygiene risk factors, or violence.

## 5.2.4 What to consider when designing a study using crowdsourcing

When designing a research study that will use crowdsourcing, there are several factors to consider, as discussed below.

### Crowd composition and crowd knowledge

It is important to consider what type of crowd is needed to conduct the task. For example, the task might require specialist knowledge (such as when gathering expert or specialist opinion), or might rely on information from laypersons. Health-related crowdsourcing exercises requiring specialist knowledge include Innocentive or Crowdmed, where complex pharmaceutical or medical problems are crowdsourced by a large crowd, and the winner is rewarded with a large sum of money. Laypersons can be extremely accurate at problem solving or conducting crowd processing tasks, such as in the case of BioGames, or for GIS solutions that require large numbers of people to report and map locations, such as OpenStreetMap. It is also important to consider the diversity of the crowd that is likely to be obtained. The more diverse the crowd, the higher the probability of obtaining a ‘smart’ crowd *(32, 48)*.

### Platform to host the call

It is important to consider the platform to host the call (or semi-open call, if choosing an expert call) for crowdsourcing submissions. Globally several platforms exist to reach laypersons, such as Amazon Mechanical Turk and Crowdflower, and other software such as Ushahidi is at least partially open-source *(38, 41)*. If people affected by the emergency are being targeted, it will be important to consider whether they are able to access the platforms without difficulty (for example, they may have limited access to mobile phones or computers with internet connections). Applications that can be considered include SMS (which may be most appropriate for those impacted), specialist data collection tools (such as using Open Data Kit) for first responders, or OpenStreetMaps for remote helpers. Finally, it is important to consider whether the data generated from the chosen platform is comparable with current data management and storage systems, and whether these can be merged if desired (*49)*.

### Crowd accessibility

The accessibility of the crowd is an important consideration. For example, the crowd may be located in a hard-to-reach area. If the target population is difficult to access, this may be challenging when advertising the call using word of mouth, online advertising or targeted enrolment. There may be barriers to entry, such as cultural sensitivities, or challenges related to reaching specialist communities with the needed knowledge (for example, diaspora communities with the ability to read messages from the affected population).

### Remuneration

Crowdsourcing in humanitarian settings primarily uses volunteered information. However, the use of platforms such as Amazon Mechanical Turk to process tasks (such as annotating images) may require some remuneration to the crowd. If members of the crowd are to be paid for their contribution, it is important to consider that the study or programme may receive many submissions over a short period of time and a pilot study may be helpful for adequately predicting and budgeting for submissions.

**Desired output**
As with any research study, a study or programme that will use crowdsourcing needs to have a clear question or purpose (Chapter 3.5). This would include careful consideration of the type of task and the best way to combine submissions (for example, aggregation or selection of the best submission). There may be ethical issues (Chapter 3.4) relating to the sensitivity of the data to be collected (for example, data on violence experienced, corruption) and care will be needed in how such data are collected, processed, stored and analysed.

**Advertising the call**
When considering the advertisement of the call it is essential to ensure that the right crowd is reached effectively. The call could be issued through a mass media campaign, word of mouth, or targeted enrolment – it should be considered which of these is most likely to reach the target population. Important factors include literacy, local customs and culture, and the reach of different media modalities.

**Study design and analysis**
In determining whether crowdsourcing is appropriate for a particular study, the balance between precision, speed and cost must be considered. It is also important to be confident that crowdsourcing is an appropriate way to generate a reliable answer to the research question.

**Quality Assurance**
Methods for quality assurance in crowdsourcing studies differ from those in traditional studies. Often, it is important to obtain multiple measurements of the same thing, and to triangulate these to verify one another. In addition, surveys might need to include questions designed specifically to identify 'malicious participants' (such as those who are answering survey questions at random).

### 5.2.5 Conclusions

Crowdsourcing is a method that uses crowds to solve problems, whether it be through harnessing knowledge of large numbers of people, capitalizing on a group of people's unique positioning to a problem (for example, through GPS-tagged submissions), or the sheer volume of a crowd and its ability to process information at a rapid scale. Existing crowdsourcing platforms are available, such as Ushahidi. Designing a programme, response or study that uses crowdsourcing will require initial thought and understanding of the questions being answered, the population forming the crowd (and how best to reach them), and whether it is the optimal method, considering trade-offs such as precision in reporting to time and cost. Crowdsourcing has been used in disaster response, and examples from outside the humanitarian context can be adapted to Health EDRM. When it is the appropriate methodology, crowdsourcing can reduce costs and improve response time, making it particularly well suited to emergency or humanitarian situations.

## 5.2.6 Key messages

- **Although crowdsourcing is still a nascent field, it has huge potential for Health EDRM *(4, 5, 50).***
- **Crowdsourcing can be a low-cost, rapid alternative to traditional data collection methods.**
- **There are several different problems that crowdsourcing can be used to solve, including crowd processing, crowd rating, crowd solving, and crowd creation.**
- **Several open-source applications exist which can be used for crowdsourcing studies.**

## 5.2.7 Further reading

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# 5.3

# Refugees and internally displaced populations

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## 5.3.1 Learning objectives

To understand the following key aspects of research with refugees and Internally Displaced Persons (IDPs):

1. The nature and characteristics of refugees and IDPs;
2. Ethical concerns surrounding migration research and approaches to address these;
3. Linguistic and cultural challenges facing refugees and the critical role of interpreters when conducting research or providing care;
4. Mental health issues of refugees and IDPs in different settings and appropriate and ethical research methods to address their needs;
5. Importance of evidence-based interventions to properly manage acute conditions and the challenges of conducting research among refugees or IDPs with acute conditions.

## 5.3.2 Introduction

The traditional role of the health sector during emergencies and disasters is response-focused on addressing and managing a single hazard. The Health EDRM framework requires the active collaboration and participation of an array of sectors and stakeholders across different levels of society to implement an approach focusing on the full spectrum of hazards, including but not limited to natural, biological, technological, and societal *(1)*. A consequence of these hazards is forced migration, which is discussed in this chapter.

Populations who have been forced to flee their homes and lands are heterogeneous in nature, and have complex reasons behind their displacement, and the destination of their fleeing journey *(2)*. Armed conflict, financial circumstances, disasters caused by natural hazards, and a lack of sufficient resources are all reasons behind forced migration. Refugees are individuals who reside outside the country of their nationality due to a well-founded fear of persecution based on their race, religion, nationality, membership of a particular social group or political opinion *(3)*.

IDPs represent those who have been forced to leave their homes and lands due to conflict, violence, disasters, or resource insecurities, but remain inside the internationally recognized borders of their home country *(2)*. At the end of 2017, there were an estimated 40 million IDPs and nearly 20 million refugees globally *(3–4)*. It is worth noting that, due to their location or circumstances, it can be more challenging to provide humanitarian support to IDPs than to refugees, which makes IDPs one of the most vulnerable populations around the world *(4)*.

Evidence-based research includes collecting, analysing, and implementing best available evidence to enhance the decision-making process *(5)*, improve the provision of health care and provide scientific evidence for Health EDRM programmes. This chapter discusses four specific topics to consider in evidence-based research among refugees and IDPs: humanitarian ethics, language and interpretation, mental health and acute care.

## 5.3.3 Humanitarian Ethics

Refugees and IDPs have been forcibly uprooted from their lands and cultures. Therefore, scholars argue that investigating and understanding their living conditions is an act of social justice. These populations continue to experience vulnerability and structural violence due to race and ethnicity, legal status and identity, as well as socioeconomic status and linguistic difficulties. Although migrants may benefit from participating in research that improves their health and wellbeing *(6)*, it is the responsibility of researchers to ensure that their investigation is conducted under humane conditions and using ethically-sound approaches.

Alongside the more general issues of ethics in Health EDRM discussed in Chapter 3.4, conducting research among refugees and IDPs carries the potential for specific ethical concerns that may arise especially during or after emergencies and disasters. Linguistic and cultural barriers may lead some refugees to engage in research without understanding its objectives, outcomes and possible risks. The variation in power between refugees and researchers might drive these vulnerable individuals, out of fear or illiteracy of their rights, to engage in research involuntarily. Furthermore, research carries the risk of causing harm to refugees and IDPs if certain population-specific considerations are not properly addressed. For example, if the investigation is conducted in a low- or middle-income country in which refugees are temporarily residing without the same rights or equal treatment as regular citizens, the privacy of their personal information might not be protected, and their safety might be unknowingly jeopardized. Indeed, refugees might be exploited, persecuted and deported should their legal status be compromised due to ongoing or previous research.

Conducting research that involves direct engagement with humans requires following certain ethical practices, such as obtaining an informed consent (Chapter 3.4). The principle strategies of informed consent are disclosure, comprehension, capacity, voluntariness and consent *(7)*. Ensuring the integrity of these four strategies while obtaining an informed consent from refugee and IDP participants may be challenging. Refugees may have limited language skills and high illiteracy rates, making it difficult or unfeasible to adequately inform them about the research procedures or to require them to read and sign informed consent forms. The heterogeneity of health literacy levels between and within refugee populations could affect the process of explaining the outcomes of the research they intend to be involved in, and any adverse effects of their involvement should these arise. Research personnel who lack adequate cultural sensitivity training may also be unable to appropriately inform refugee participants about the nature of the research, which could thereby compromise the integrity of the informed consent process.

Before starting a research study among refugees and IDPs, researchers should comprehensively assess the benefits of undertaking the study for this specific population, the participants undergoing the assessment and the society as a whole. They also need to recognize the importance of protecting the confidentiality and privacy of their participants. Essential identity and demographic data such as names, dates of birth and current residences should only be collected when the benefits of this procedure far outweigh the harms. If such data are collected, anonymization or pseudonymization procedures should be used to protect participants and ensure their confidentiality. Hard copies should be kept in secure areas and personal data should be safeguarded by comprehensive safety systems or separated physically from other collected materials. All electronic files should be encrypted and protected by passwords, and access to these files should be limited to personnel who are conducting the particular research study.

Finally, the leaders of the research have the responsibility of adequately training their staff and interpreters to use culturally sensitive approaches when explaining the nature of their research and to conduct the informed consent and data collection processes adequately, while avoiding any cognitive biases that might affect the quality of the research.

### Case Study 5.3.1
### Example of important cultural issues in a research project with Syrian refugees in Lebanon

A doctoral student was undertaking a qualitative migration research project as part of her dissertation. She planned to go to Lebanon and conduct semi-structured interviews with Syrian refugees to understand their lived experiences during a transitional period.

Upon arrival in Lebanon, she recruited an Arabic-speaking research assistant to help with the field work and the interpretation processes, but the assistant voiced concerns about privacy and confidentiality. She recognized why collecting names of participants might jeopardize their privacy and safety. She made the ethically-sound decision not to collect their names and decided to perform a sex- and gender-based analysis instead.

### 5.3.4 Language and interpretation

Language and cultural barriers disrupt communication between medical practitioners and refugees, limiting their access to and maintenance of treatment, increasing their use of emergency services, and reducing their health-related quality of life. Caring for refugees is challenging due to the complexity of their communication barriers, health conditions and their limited health system literacy *(8-11)*. Limited local language proficiency may lead to poorer treatment adherence *(12)*, impede refugees' access to fundamental services and life necessities such as housing *(13)*, and negatively impact their social capital, because the majority find themselves unable to reach out and extend their social networks beyond those who speak their mother tongue *(14)*. In Canada, limited local language proficiency was associated with a rapid decline in the health status of newly arriving refugees and other immigrants *(15)*. Some of these communication difficulties are related to cultural differences and possibly fear of physicians *(16)*. Emergency practitioners, however, can mitigate the harms of communication barriers experienced by refugees through enhancing the appropriateness of the health care they provide *(17-18)*.

High-income countries have attempted to implement interpretation services within their social and healthcare systems to aid refugees and other migrants with poor language skills. This approach helped refugees access, navigate and maintain social and healthcare services *(19)*. Interpreters act as a liaison between both ends of the conversation and play a pivotal role in overcoming language barriers. They should possess certain attributes that are fundamental to their role, such as the ability to fluently communicate in the native tongue of the refugee as well as the official language of the healthcare or social service provider. Furthermore, evidence shows that medical interpreters should receive proper training in medical terminology and interpretation to ensure the quality of their work *(20)*. Interpreters should not take a central role of the conversation but rather maintain their position of support to the quality and accuracy of this interaction. It is preferable for them to have background or cultural resemblances to that of the refugee so that they are able to understand and properly interpret the indirect gestures and expressions which could be specific to this background or culture. However, local interpreters are very likely to be recruited from the same community as the study participants, a practice that could bias the interview process and give rise to confidentiality concerns and misinterpretations generated by cultural assumptions or taboos. Finally, interpreters should be trained on the importance of respecting the confidentiality of their clients and the application of procedures that protect their privacy and the privacy of the information they exchange.

In the field of migration research, using interpreters can improve the quality of the evidence. In qualitative research (Chapter 4.12), interpreters narrow the gap between the perceptions of refugee participants and the understanding of the researchers conducting the investigation. In quantitative research, interpreters facilitate the exchange of data from and to refugee participants. However, there are several limitations to using interpreters in migration research. For example, certain refugee or IDP populations might have an unconscious mistrust of locally recruited interpreters and would be suspicious of any enquiries, which might make them feel uncomfortable about participating in research. Moreover, the lack of human and timely resources may impede the data collection process, and therefore the quantity of interpreters becomes a determinant to the quality of the research. The accuracy of interpretation may also affect the quality of evidence, mainly because verification of responses is limited. Finally, interpreters could allow their cognitive biases to interfere in the process of exchanging information, which, in return, affect the quality of the data collected.

### 5.3.5 Mental health research

Disasters and humanitarian crises negatively impact the mental health status of affected populations (Chapter 5.1). Mental health problems could be the result of pre-existing illnesses, emergency-induced disorders or conditions caused by the humanitarian response to disasters. Therefore, a sound and effective response to a health emergency or disaster should consider addressing, investigating and managing the mental health conditions of affected populations. Refugees and IDPs who experience or witness traumatic events or violence before their resettlement are at a higher risk for developing mental health conditions such as depression, anxiety or PTSD *(21-23)*. Such events could have been witnessed or experienced before fleeing (when individuals have to give up their properties, jobs, education, as well as family and social networks), during their migration journey (when some may be faced by precarious events and substandard living conditions), or after their arrival to the host country (where they may undergo prolonged asylum-seeking processes, stigmatization, and barriers to accessing their fundamental life needs) *(13, 24)*.

Conducting mental health research among refugees or IDPs poses several challenges that must be addressed adequately to ensure the proper conduct of research among these vulnerable populations. Firstly, the physical environment surrounding refugee participants might be inadequate or unavailable to conduct research. Secondly, some researchers may resort to employing the services of family members as interpreters. This practice gives rise to ethical concerns because family members cannot be objective interpreters, especially when discussing frequently stigmatized issues such as mental health problems. Thirdly, the limited time availability of refugees and IDPs because of work or family health issues could lengthen the research process and require further funding. Furthermore, investigating past traumatic events by regular research staff or interviewers may cause some participants to relive these events, which could ignite their psychiatric symptoms and cause them harm *(25)*. Lastly, externally validating or "generalizing" the findings of mental health research to broader refugee or IDP populations is challenging because those who are willing to participate in a study examining their mental health problems may be radically atypical of the wider population.

Multiple procedures must be followed when conducting research among refugees or IDPs. Researchers must ensure that their research is performed in a secure and quiet setting with adequate privacy measures that the participants feel comfortable about. Offering participants a monetary compensation for their time should not be the sole reason for their participation in research without understanding its nature. Therefore, declaring the provision of any financial or other incentives for participation should occur after explaining the research procedures and outcomes intended. It may be beneficial for researchers to explore proxies for psychological distress, such as sleep disturbance or decreased social functionality, especially in cultures where mental health problems are highly stigmatized. Moreover, when applying for funding (Chapter 6.3), researchers should explain that the process may take longer than expected, leading to a need for more funding to ensure the completion of the proposed study. All interview procedures must be concise and preferably conducted somewhere close to the participant's residence. Lastly, professional psychologists or physicians with expertise in dealing with trauma-induced mental health conditions must be present during the questioning process to ensure the proper management of acute mental health symptoms should they arise.

When conducting research using existing studies, systematic reviews and meta-analyses represent the most feasible and accurate approach to consider when dealing with this vulnerable population (Chapter 2.6). A systematic review is a research methodology that aims to identify, critically appraise and synthesize all the empirical evidence that meets pre-specified eligibility criteria to answer a research question *(26)*. Meta-analyses usually accompany systematic reviews and provide more clear-cut and explicit estimates of the effects of studied interventions *(27)*. However, conducting systematic reviews may present some challenges: the process is time consuming and may not be suitable for answering a question that has not yet been studied. Furthermore, the accuracy and certainty of findings depend heavily on the searches done by the reviewers' and the quality of the studies they review.

**Case Study 5.3.2**
**Use of a systematic review to assess psychosocial services and programmes for refugees and IDPs *(28)***

There is a large body of literature on psychosocial services and programmes. However, evidence on the effectiveness of these interventions among refugees and asylum seekers is sparse and not adequately quantified. Therefore, Nosè and colleagues *(28)* conducted a systematic review and meta-analysis on the effectiveness of such services.

To ensure a robust and systematic review of literature, they set inclusion criteria that answered their research question and defined the population, interventions, comparisons, and outcomes of interest. They searched for controlled trials of adult refugees and asylum seekers in high income countries that had compared the effects of a psychosocial intervention versus no intervention, usual care, or minimal interventions, to assess post-traumatic and depressive symptoms.

The findings showed that psychosocial interventions such as narrative exposure therapy (NET) were effective in decreasing PTSD symptoms as well as depressive symptoms compared to control groups. However, these findings are limited to adult refugees and asylum seekers in high-income countries and cannot be generalized to IDPs, migrant children, or refugees in low- and middle-income countries. Furthermore, the definition of refugees differed across studies, which could camouflage certain population specificities that should be considered.

The inability to generalize findings due to population heterogeneity may limit the evidence-informed decision making process. Therefore, groups such as the Grading of Recommendations, Development and Evaluation (GRADE) recommend decreasing the certainty of evidence should researchers detect any indirectness affecting the effectiveness of a certain intervention *(29)*.

## 5.3.6 Acute Care

Although refugees and migrants are likely to be in good health prior to fleeing, their health status might be jeopardized while in transition or living in substandard conditions after departure from their homes and lands *(24)*. The interaction of overcrowded environments, contaminated water, poor sanitation and low access to health services such as vaccination serves as a breeding ground for illnesses to re-emerge. Communicable diseases make up almost 90% of consultations in refugee settlements *(30)*. Diphtheria is an example of a vaccine-preventable disease with rare occurrence rates, even in low- and middle-income countries. The pathogen behind diphtheria, however, has spread among Rohingya refugees in Bangladesh due to their congested and overcrowded living conditions, and the lack of vaccination coverage among them *(31)*. Cholera is another example of an opportunistic water diarrhoeal disease that spread among Yemeni children because of limited access to clean water and sanitation resources *(32-34)*.

Managing acute conditions among vulnerable populations requires evidence-based interventions that are proven to be rapid and effective.

New research among refugees and IDPs with acute conditions should only be undertaken if it addresses a critical issue with high prevalence among this population, and assesses a research question that a review of existing research or data does not provide an answer to (Chapter 3.6). Research protocols must be well designed to reflect the logistical and ethical challenges of conducting research among refugees and IDPs, as well as the proposed practices to ensure the success of techniques such as randomization (Chapter 4.1) and recruitment among patients with acute conditions. Moreover, protocols must describe, in detail, the use of privacy methods to ensure the confidentiality of participants in an emergency environment.

When conducting the investigation, researchers must acknowledge the critical physiological and cognitive conditions that refugees and IDPs might experience. Their condition might mean that they are in pain, frightened, unaware of their rights within a new healthcare system, illiterate of their health conditions, or unable to explain their symptoms due to language barriers. They might also have impaired cognition, preventing them from giving an informed consent. Refugees and IDPs may also think that treatment is contingent to their participation in the research study. The researcher, therefore, must have sound and culturally appropriate communication skills to help inform potential participants about the nature of research, the benefits and harms of undergoing it, and their right to refuse participation without any penalty. If capacity to provide an informed consent is jeopardized due to cognitive impairment, the researchers must obtain an “a priori” approval from an ethics board or committee to employ other methods of consent-acquiring processes such as proxy, prospective or deferred consent (Chapter 3.4). Nonetheless, researchers must always act in the best interest of the participant. Lastly, equity considerations must be addressed and strict rules must be imposed to prevent researchers, interpreters, or outcome assessors from discriminating against participants based on their gender, ethnicity, religion, sexual orientation or political opinion.

**Case study 5.3.3 Identifying acute health needs in refugees and IDPs *(35)***

Refugee populations frequently move together in large heterogenous groups. These groups will often reach a political border or face a natural barrier that will lead to the formation of a temporary camp. The United Nations High Commissioner for Refugees (UNHCR) plays a major role in supporting the road, tent and health infrastructure for these camps. Nonetheless, the sub-standard living conditions and congestion in these camps is a risk factor for developing acute illnesses and conditions.

Rapid needs assessment surveys (Chapter 2.1) can play an important and timely role of mitigating acute health conditions. These detect the demographics of the populations, pregnant women, elderly, young children and cases of acute diarrhoea and acute respiratory infection or other communicable disease outbreaks. Multiple survey tools now exist online such as EPI Info from the US Centers for Disease Control and Prevention (CDC), which provides support for researchers and public health professionals as they prepare the questionnaire, enter data and conduct rapid analysis *(36)*. Most rapid surveys are done in collaboration with local staff.

Hurricane Katrina forced many families to move from their homes into other cities, such as Denver, Colorado. Ghosh and colleagues conducted a rapid needs assessment survey to identify and examine the acute and contextual medical and non-medical needs of these populations that moved following the hurricane. Certain unique needs emerged, such as the necessity to educate individuals on the high altitude of the city of Denver, and what they can do to overcome altitude-related symptoms *(35)*.

## 5.3.7 Conclusions

Conducting research for refugees and internally displaced populations can be rewarding both for vulnerable migrants and for health practitioners. Although research engagement can bring evidence-based practices and programmes for migrant specific conditions, researchers need to be vigilant for any ethical concerns that may arise. Training research staff on cultural sensitivity and adapting a comprehensive and explicit informed consent process are good practices to follow when conducting research with vulnerable populations. Field research for mental illness and acute care conditions should only be undertaken when the need for such investigation outweighs any potential harms. Knowledge syntheses such as systematic reviews and meta-analyses may improve the precision of research, reduce bias and limit unnecessary harms to local populations.

### 5.3.8 Key messages

- **Researchers need to consider population-specific ethical concerns when conducting research among refugees or IDPs, such as obtaining a comprehensive informed consent.**
- **The linguistic barriers that refugees face require the services of interpreters when providing care or conducting research. Researchers need to acknowledge the confidentiality challenges and cognitive biases that may arise when using interpreters and work to overcome them.**
- **Refugees and IDPs are at a disproportionately higher risk of psychiatric disorders. Mental health research among these vulnerable populations is challenging and requires ethical research methods.**
- **Efficient management of acute care conditions among refugees and IDPs requires evidence-based research. Researchers should be transparent when planning their research and should have sound communication skills to explain its nature to refugees and IDPs.**

### 5.3.9 Further reading

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# 5.4

# Indigenous peoples

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## 5.4.1 Learning objectives

To understand the following:

1. Methodologies addressing the health needs of indigenous peoples;
2. The contributions of indigenous knowledge and practices to research and evidence in Health EDRM;
3. Key inputs from prior research to support effective inclusion of Health EDRM approaches among indigenous communities.

## 5.4.2 Introduction

Indigenous peoples have faced the risks of emergencies and disasters for generations and have applied indigenous knowledge and practices in efforts to reduce the risks and impacts of these events, and build the resilience of their communities. The Sendai Framework for Disaster Risk Reduction 2015-2030, which was adopted by UN member States at the Third UN World Conference on Disaster Risk Reduction, gives emphasis to the integration of traditional indigenous and local knowledge and practices, to complement the development and implementation of disaster risk management policies, strategies, plans and programmes tailored to localities and context *(1)*.

Indigenous peoples are dedicated to persevering, developing, and transmitting their land and ethnic identities to future generations to further their existence as communities with distinct cultures, institutions, and governance *(2)*.

Indigenous communities may be disproportionately impacted by a variety of emergencies and disasters *(3)*. They often endure multiple forms of discrimination and exclusion, resulting in significant inequities, including high levels of poverty and violence, and consequently, the denial of their individual and collective rights (*4)*. The social and economic disadvantage that some communities face leads to decreased access to health services and to poor infrastructure, posing a long-term challenge to resilience. Although indigenous peoples have close relationships with the land, these regions may be compromised due to human- activities such as resource mining, forestry and agriculture, which may leave them vulnerable to the impacts of emergencies and disasters. On the other hand, there are numerous examples of indigenous communities having enhanced adaptive capacity and thus resilience in disaster settings despite socioeconomic deprivation.

Chapters 3.4 and 6.4 discuss ethical issues relevant to research; additional ethical considerations must be put into place to ensure effective inclusion and respect for the rights of indigenous peoples and the use of indigenous knowledge and practices in Health EDRM. There are critical adaptive capacities, networks and bonds among indigenous peoples, as well as additional vulnerabilities, such as social, economic, physical, and environmental factors, that need to be considered in methodological approaches to undertaking research in partnership with indigenous peoples.

In response to the challenges faced by indigenous peoples, the PAHO Member States approved the first PAHO Policy on Ethnicity and Health in 2017. Representatives from indigenous peoples, Afrodescendants, and Roma populations, among others, participated in the development of this policy and committed to supporting its implementation. This policy is aimed at improving, among other things, the health of indigenous peoples in the Americas, while acknowledging the different situations and challenges of these populations in diverse contexts. It is based on recognizing the need for an intercultural approach to health and equal treatment of the different groups from the standpoint of equality and mutual respect. The policy focuses on five lines of action to address the health of ethnic groups: a) the production of evidence; b) the promotion of policy action; c) social participation and strategic partnerships; d) recognition of ancestral knowledge and traditional and complementary medicine; and e) capacity development at all levels. The PAHO Policy on Ethnicity and Health acknowledges the importance of adopting an intercultural approach to address inequities in health *(4)* and is often used as a policy reference at the global level.

This chapter outlines key methodologies and examples to support effective research with indigenous communities, while highlighting the need for any such collaboration to take into account important cultural differences and be based on mutual respect and benefit to both parties. The PAHO Policy on Ethnicity and Health, along with the Sendai Framework for Disaster Risk Reduction and the WHO Health EDRM Framework, are taken into consideration throughout this chapter.

## 5.4.3 Production of evidence

Understanding the health needs of indigenous peoples is important for the implementation of Health EDRM, in particular for the assessment of risks, including the analysis of exposure, vulnerabilities and capacities. The health data on indigenous peoples may be non-representative, in part due to the lack of disaggregation of data by ethnic origin, and misclassification and underestimation remain key challenges to effective measurement and understanding of indigenous health status. While governments, UN organizations and researchers have made efforts to disaggregate data by ethnic origin, these methods have not always been systematically implemented. The varying definitions of ethnicity across censuses and health records can cause inaccuracies in typical data collection methods (such as national registries), contributing to the lack of health data available among indigenous populations and so significant gaps in data remain.

Different approaches are being employed to improve data and evidence on the health needs of indigenous communities. Data linkage methodologies that collate and cross-reference data from various sources are increasingly being used to improve the accuracy of existing data. Variables such as their recognition of ancestral lands, the main language spoken at home, financial stress over the last year, and self-assessed health status have been used among Aboriginal populations in Australia to compare against census data, and to assess national data compared with qualitative collection *(5)*. Qualitative data collection methods, as discussed in Chapter 4.12, can help enhance understanding of the health needs and experiences of indigenous peoples, and some authors have demonstrated that conducting semi-structured interviews have produced useful insights into the needs of the communities in Health EDRM *(5–6)*. Meanwhile, interactive and collaborative methods of participatory research have shown success in other settings. These techniques include mapping, timeline assessments, trend analyses, daily activity schedules, seasonal diagrams, and likelihood analyses *(7)*.

Participatory research can provide meaningful insight into indigenous health needs. However, outside researchers should ensure they are not imposing their own theoretical and methodological frameworks into participatory activities. It is critical that research is viewed as a partnership, and that an interviewer's relationship with the communities is not a superficial one or just for the sole purpose of data collection *(8)*. This could be perceived as disrespectful and may be damaging to the goal of exchanging information and equitable co-production of research. Instead, such methods should always be based on meaningful consultation, be of clear mutual benefit, and recognize and respect indigenous approaches to health and to emergencies, including disease outbreaks. It is important to collect information on the potential for disease outbreak within these communities. This should include an assessment of what taboos or differing perceptions may exist around certain diseases and how to address them in a culturally appropriate context *(9)*. Meaningful participation of community members in data collection and use is important, as well as ensuring the representation of both women and men of all ages, recognizing the potential impact of gendered and intersecting vulnerabilities in Health EDRM *(4)* .

### 5.4.4 Social participation and strategic partnerships

PAHO's Policy on Ethnicity and Health *(4)* states that it is essential to promote social and strategic partnerships in line with the national context, while ensuring an accurate representation of both men and women in the process of preparing for health-related activities. This area of intervention seeks to promote effective participation, joint efforts, commitment and strategic partnerships among health authorities, other state institutions, local organizations and the general population to foster action to increase inclusion, equity and equality. In turn, this can better guide research practices in a respectful and effective manner.

While the methodology of data collection is crucial in assessing the needs of indigenous peoples in Health EDRM, it is also imperative that the existing institutions and organizations within these communities are included in the decision-making process, in partnership with national and international organizations *(10)*. Indigenous peoples are best placed to make an assessment of the needs of their community, and this perspective is crucial in managing the risk of emergencies prior to their occurrence. These communities are often marginalized. Researchers have described a denial of their right to self-determination by a postcolonial "developmentalist narrative" in which indigenous peoples are systematically refused and excluded from participation in sustainable development projects *(11–12)*. This leaves their land and resources especially vulnerable to hazards during disasters, yet partnering with them in preparedness actions has been shown to improve post-disaster responses.

Policies only enacted at the governmental level, without the meaningful inclusion and participation of indigenous bodies, have been shown to further enable the cycles of colonization and marginalization *(11)*. Drawing on research examining pre- and post-disaster conditions among indigenous peoples in New Zealand, three types of participation groups can be considered when implementing disaster-based policies: participation led by government, participation led through pre-existing community organizations, and participation through the grassroots movements that arise situationally *(13–14)*. Furthermore, it is important to consider public-private partnerships that stem from co-governance agreements, which are becoming increasingly common between indigenous collectives and central and local government in disaster settings *(13, 15–16)*. There are many examples of indigenous communities assuming leadership in these situations, establishing their own emergency plans and actions to then collaborate with outside governing bodies.

Research has shown that effective processes in promoting the involvement of indigenous organizations within the community in Health EDRM, including both preparedness and response capacities, often include assessments of physical infrastructure *(17)*. Community members are more aware of the areas for improvement than outside organizations, who may be unfamiliar with their infrastructure and systems *(18–19)*. This need becomes even greater with the increasing impacts of climate change and its effect on indigenous communities. In order to properly assess the needs of the communities in vulnerable terrains, researchers should take care to ensure they are fostering indigenous participation in sharing knowledge of how nature has impacted their people in previous generations as well *(19–20)* . As outlined in the Sendai Framework, community-based approaches may need to be modified to address vulnerable groups such as the elderly in disaster situations *(1)*.

### 5.4.5 Recognition of ancestral knowledge and traditional and complementary medicine

The recognition of ancestral knowledge aims at promoting knowledge dialogue to facilitate the development and strengthening of intercultural health models as a way of achieving people- and community-centered health care *(4)*, including disaster risk reduction plans.

A widely-accepted practice of improving Health EDRM among indigenous peoples is the incorporation of indigenous knowledge into planning for emergencies and disasters. Indigenous knowledge has been defined in a variety of ways. UNESCO describes local and indigenous knowledge as follows:

The understandings, skills and philosophies developed by societies with long histories of interaction with their natural surroundings. For rural and indigenous peoples, local knowledge informs decision-making about fundamental aspects of day-to-day life. This knowledge is integral to a cultural complex that also encompasses language, systems of classification, resource use practices, social interactions, ritual and spirituality. These unique ways of knowing are important facets of the world's cultural diversity, and provide a foundation for locally-appropriate sustainable development *(21)*.

This information can improve scientific knowledge and increase the acceptance of policies within the community by drawing on this understanding of the interaction between culture, resources, and the environment *(22–25).*

Before the 2004 tsunami in the Indian Ocean, the importance of indigenous knowledge was largely underestimated even though indigenous knowledge of how to respond to signs of incoming tsunami waves had saved many indigenous lives *(26–27)*. Elsewhere, purposive sampling of indigenous members within a region of the Republic of Zimbabwe prone to extreme flooding revealed that their study of cloud patterns and the restlessness of a specific species of bird had been studied and this knowledge passed down as a warning sign for imminent heavy rains *(28)* . The Tikopia Island population in the Solomon Islands were prepared for Cyclone Zoe in 2002 by their use of traditional sturdy housing structures that had been part of the cultural knowledge for generations, as well as knowing the locations of overhanging rocks to use as shelter when the storm hit *(29)*. These examples demonstrate that indigenous communities have been drawing on indigenous knowledge to ensure resilience in the face of environmental hazards for long periods of time, and that much remains to be done to effectively incorporate these insights into disaster preparedness and response strategies.

Bridging traditional knowledge and western science is more impactful when they are viewed not as two separate ways of managing risks of emergencies and disasters, but as a collaborative sharing of information from several sources that can provide successful plans of action *(30–31)*. This also applies to the different perceptions that researchers and indigenous communities may have regarding the definition and description of a hazard. Certain events may be viewed as a potential disaster by some scientific communities, while for an indigenous community, the same events may be perceived as something that they have developed the knowledge to handle routinely over generations *(12, 32–33).* Consequently, researchers and policymakers should take care that proposed actions are shaped in consultation with the community – and be guided by the community's insights as to what would be considered hazardous. This has been referred to as the process of "guided discovery", in letting the communities highlight the areas of importance, in order for researchers to then collaborate in developing a plan for disaster risk reduction *(7)*. Research has shown that it is an effective practice to subdivide groups within the community by type of knowledge and who is best served to communicate this into emergency and disaster planning *(32)*. This includes knowledge such as usage of the land, input from elders within the community, or even the division by gender if appropriate within the community's culture ,so that people feel they can speak freely *(32)*.

It is through "knowledge dialogues" that indigenous peoples can lead the conversation and provide information from their own perspective regarding emergencies and disasters. Furthermore, through continuous knowledge dialogues, indigenous peoples can gradually determine whether they need to modify or transform their practices, living conditions, and knowledge of the risks they have in the community.

It is also recommended to involve knowledge stemming from oral traditions of indigenous peoples, particularly since these are not frequently documented ,and thus sometimes discredited by researchers *(32)*. For populations maintaining oral knowledge traditions, rather than written, previous research has found that immersive fieldwork provides an effective approach to learn from oral tradition about the nature of past events and to be able to document them for future collaboration *(33–34)*. As storytelling related to indigenous knowledge of disaster risks, situations and practice comes embedded in the ways of life within communities, methodologies that respectfully analyse and record these stories with the involvement of elders support more culturally relevant disaster risk management *(12, 33)*.

While there has been improved documenting of the implementation of indigenous knowledge and practices, particularly in relation to natural and environmental hazards and more recently climate change related disasters, there is still work to be done to mainstream this into policy approaches. Therefore, research outcomes recommend that the strategic partnerships established in response to previous emergencies and disasters work towards greater implementation of indigenous knowledge and traditions. This can be used, for example, in disseminating warnings before events in both traditional scientific language and through the medium of indigenous language and cultural norms as well *(34)*.

### Case Study 5.4.1
### Kaupapa Māori - Indigenous Research Methodology and Health in Disasters

Kaupapa Māori research is a New Zealand-based indigenous research approach that combines indigenous research theory, methodology and design *(35)*. Research is developed by and for Māori, addresses Māori concerns, and is implemented by Māori researchers in accordance with Māori cultural values and research practices *(36–37)*.

A qualitative research project was developed to identify cultural attributes that enhanced the wellbeing of Māori during and after the 2010-2011 Canterbury Earthquakes. A Māori research methodology, Te Whakamāramatanga *(38)*, underpinned by cultural values and practices, shaped project implementation, facilitating a research partnership between the researchers and Māori partners, Ngāi Tahu. Tribal connections and external relationships were leveraged to recruit participants. Institutional ethical requirements and the tribe's cultural imperatives were met. Acknowledgment of the tribe's Mana motuhake (self-determination and autonomy), their collective authority, agency, action and accountabilities in relation to the research, generated community trust. Whakaritenga (negotiation) and whakaaetanga (acceptance, agreement, consent) were continually actioned. Data collection explored Māori views of the response to the earthquakes and 70 participants' narratives were collected during interviews and hui (group meetings). Interview topics were jointly agreed, while interviews were transcribed verbatim and member checked. Māori cultural concepts framed narrative analyses of participants' talk. Investigator and theoretical triangulation processes reduced data misinterpretation. Researchers liaised with participants to ensure themes reflected Māori experiences.

Thematic results included the effectiveness of Māori responses to the earthquakes; concerns (such as invisibility of Māori concerns and health needs) and cultural beliefs, values and practices contributed to Māori recovery and could enhance community resilience. Participants' recommendations for Māori planning for disaster preparedness were also documented. Results highlighted the speed and effectiveness of the Māori response to community needs. Māori resources encompassed mobile emergency medical teams, primary care, and psycho-social services, financial supplements, shelters, food, clothing and fresh water as well as free legal guidance regarding government benefits and insurance *(38)*. Results also drew attention to the ways formal emergency management othered Māori in the earthquake response *(12)*. Publications were co-authored with Maori partners who retained intellectual property rights over cultural knowledge, and shared property rights for new knowledge with the researchers.

Findings have informed changes to emergency management policies and practices. The role of Māori in facilitating community resilience to disasters, has also been acknowledged by central government *(39, 40)*, and related amendments to disaster management legislation, signaled.

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### Case Study 5.4.2
### Yi-minority Community in Sichuan Province, China

Geographical location plays an important role in explaining ethnic vulnerabilities to disasters. There are 55 ethnic minority groups in the People's Republic of China, constituting 8.49% of the country's total population *(41)*. They have different dialects, cultural practices, livelihoods, and social traditions within the boundary of China; nevertheless, most of them are also characterized by the remoteness of their settlements, which has been associated with inadequate access to health services as well as to education. Evidence from previous disasters shows that these communities have been highly exposed to hazards and demonstrate a low resilience to loss *(42)*.

A survey undertaken to inform a Health EDRM programme for the Yi-minority community in Sichuan province, showed that the Yi population, who live in a mountainous landscape with poor road conditions, lacked disaster preparedness *(43)*. It also found that previous disaster experience, including a major flood in 2012, had not been a good predictor for future disaster preparedness – despite an increasing risk of disaster in this rural mountainous area. Informed by these findings, a number of health measures were designed in order to strengthen villagers' disaster preparedness. This included the preparation of household disaster kits and oral rehydration solution recipes. These interventions were tailored to the need of the community and implemented in a way that was culturally acceptable – with a focus on providing the necessary tools for self-empowerment and improved resilience.

To truly address the need of these communities before, during and after emergencies and disasters, it is of utmost importance that research informs health strategies and actions about potential differences between ethnic and non-ethnic minorities. Factors to take into account may include diversities in demographic patterns, literacy rate, language and occupation. Effective risk communication (see Chapter 4.11) must be tailored to the literacy rate and languages (mostly dialects) of the community, while age and occupation will be key predictors of health status and responsiveness to the risks and impacts of disasters.

## 5.4.6 Conclusions

In summary, existing research methodologies concerning Health EDRM among indigenous peoples are scarce and often non-representative. Such methodologies can benefit from certain advances, such as the Sendai Framework, the Health Emergency and Disaster Risk Management Framework and incorporation of lines of action addressed in the 2017 PAHO Policy on Ethnicity and Health. They may also benefit from being modified to include collection of disaggregated data and to encourage participation and community engagement – which are crucial in any action that may seek to strengthen Health EDRM among indigenous peoples.

## 5.4.7 Key messages

- **Indigenous peoples must be meaningfully included in the development and implementation of Health EDRM policy, planning, practice and research to ensure that the approaches used are culturally and linguistically relevant.**
- **True partnership with indigenous peoples and effective engagement of indigenous peoples in Health EDRM is crucial. It is important to assess what aspects of communication, among other areas, need to be improved upon to meet the community's needs.**
- **It is critical that research is viewed as a partnership which respects the leadership, empowerment and full consent of indigenous peoples. Indigenous people are best placed to make an assessment of the needs of their community, and this perspective is crucial in risk management and research.**
- **International and national agencies and other organizations need to be held accountable in including indigenous peoples in Health EDRM initiatives, particularly the recognition of knowledge, practice and needs of indigenous peoples, collaboration with indigenous people. and incorporation of indigenous knowledge and practice into regional, national, and international emergency and disaster risk management strategies and plans.**

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# How to become a researcher

# 6.0

# 6.1

# How to become a successful researcher

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## 6.1.1 Learning objectives

To understand the lifelong joys and challenges of becoming a successful researcher, by appreciating the importance and value of:

1. Gain a mastery of varied research methodologies to answer timely scientific questions.
2. Field research conducted in real-world and natural environments, which can give the researcher a deeper understanding and appreciation of the research topics and a respect for the research subjects.
3. The ability to work autonomously, set clear goals, be organized, and have a good research plan while meeting deadlines and expectations.
4. Mentorship and of working collaboratively with other researchers, mentors, learning to lead with questions using mature listening and communication skills.

## 6.1.2 Introduction

The enormous progress made in improving health and life spans during the 20th century is owed in no small part to the impact of high-quality research. *(1)* However, researchers, the public and policy makers are increasingly talking about the challenges of effectively delivering quality care, and a growing implementation gap *(2-4).* This gap manifests as a lack of success in translating research-based scientific findings into routine practice, policy and personal behavior change. Other concerns being raised include those about research waste – either because the right research is not being done, or because the findings of the right research are not being implemented *(5)*. This also holds true in supporting and applying Health EDRM in disaster preparedness and response.

> *"Every time a scientific paper presents a bit of data, an error bar – a quiet but insistent reminder that no knowledge is complete or perfect, accompanies it. The most each generation can hope for is to reduce the error bars a little, and to add to the body of data to which error bars apply".*

This quote, from Carl Sagan's The Demon Haunted World *(6)*, highlights the challenges of pursuing a career in medical research, where one can contribute to addressing the most pressing questions of the day in the constantly emerging challenges of science, such as when managing the aftermath of natural or man-made disasters.

Our aim in this chapter, and of this book as a whole, is to encourage the reader to become passionate about the process of generating, advocating for, and learning how to use high quality and effective research to help support and drive better public awareness, discourse and health policy.

### 6.1.3 How to Become a Researcher?

If you want to contribute to the body of knowledge and understanding of how to improve Health EDRM while implementing more resilient systems, it is important to understand and learn about research methods and how best to apply them*(7)*. Being a researcher can be the most powerful, empowering and learning experience of your career – it can be challenging and fascinating to address real pain and suffering, while seeing healthcare in its stark reality and learning to improve the delivery of public health by mapping out the full potential of policy interventions *(8)* and, if appropriate, perhaps working at the frontline of the humanitarian response or in an active pandemic. Talking to practitioners and administrators, listening carefully to the concerns of front line workers and leaders, and what drives their understanding will help you appreciate their behavioural choices or mindsets when offering potential solutions to address these concerns *(9)*. Observing their interactions with patients and the public can offer you a new perspective on what frightened, vulnerable people in disasters and emergencies really feel and need, and, what types of research communication can get in the way of effective implementation of public policy, even in the most organized and mature social systems.

Devising and conducting research, for example, to investigate the epidemiological basis of a contagious disease, such as with the novel coronavirus in 2020, to understand issues around weapons of mass destruction *(10)*, or to identify effective public health interventions requires the ability to assess and address complex questions. This might relate, for example, to the causes of earthquake disasters and ways to prepare public health systems to deal with disasters caused by natural or human-induced hazards. Finally, effective written and oral communication skills, and having the ability to present and defend one's ideas and recommendations, are essential to becoming a successful and independent researcher.

Many young people embark on a career in research with little guidance provided about the expectations and immense challenges awaiting them. There is often no set career path, no clear milestones, and limited leadership to guide young students on the most effective pathways. The roadmap to becoming a successful researcher is complex and rather opaque, as the profession demands distinctive skills and expertise along with a long mandatory formal education *(11)*.

The cornerstone of pursuing a career in research starts with obtaining a formal education in areas such as the biological and medical sciences, public health or the wider healthcare disciplines. One might seek to study and train at an influential university or healthcare organization, aiming for a formal degree such as a bachelor's or master's degree, or ideally at the doctoral level, such as a public health or medical doctorate or PhD. After completing a formal programme with tailored courses, the next milestone towards the development of a career in medical research is participating in a research-based internship or joining an existing ongoing study. In most graduate schools, participating in a research internship and undertaking a research project is an essential part of the exclusively designed curriculum. This will allow for opportunities to be mentored by a practitioner or a research scientist and collaborate with other researchers tackling real public health issues, such as infectious disease pandemics, medication safety, or the mental health challenges of displaced persons (Chapters 5.1 and 5.3).

As a junior researcher, you may be required to assist a senior scientist in devising trials, collecting data (including conducting analytical data mining), interpretation of results and writing a scientific manuscript that can be critically replicated and tested by peers and is generalizable to other settings. A research career revolves around investigations – for example, to understand clinical symptoms caused by diseases or an aberrant human behaviour – and rigorous laboratory or field work – such as to assess the impact of vaccinating refugees in austere environments or the impact of people congregating without social distancing during a pandemic. To be a researcher, formal education will not suffice, though; working in a team on high-quality research requires essential set of key skills, including:

- creative critical thinking, free from prejudice, exercising healthy scepticism and not accepting anything at face value, including the ability to reflect and use hindsight and logical reasoning
- problem solving abilities
- logical decision making
- accurate and verifiable data collecting, and attention to detail
- assimilating critical data and feedback
- drawing clear and meaningful conclusions
- developing a strong work ethic
- performance management of self and others
- good project planning and management
- effective interpersonal communication skills
- identifying and citing appropriate sources
- team building
- excellent writing skills to enable you to present your work in a clear and transparent way (Chapter 6.7) in a peer-reviewed journal of good standing, while avoiding predatory publishers *(12)*.

You will need to read widely to prepare yourself ,covering academic papers and reference articles in your research area but also in different areas, and produce good quality academic articles. This practice will help you to better assimilate and appreciate the vast knowledge in your domain and increase the quality and impact of your writing and professional judgement skills.

Building a valued scientific network, learning to appreciate your peers (in your own discipline and others) and those from other sectors, establishing a reputation for humble inquiry, probing questions, integrity and generosity, will help to attract other researchers to collaborate with you in building a great research team. *(9)*

### 6.1.4 Establish your research interests

Research interests often spawn from one's own background and curiosity. Practitioners in health care and other areas are blessed if they keep their mind's eye open and remain curious, and are exposed to many potential research questions during their routine clinical work. Consider the following four questions as you narrow your research focus in Health EDRM and support a successful line of inquiry into disaster risk management. This will also be key as you prepare a grant application for funding your research (Chapter 6.3):

- Why is this research needed now?
- Who cares about this phenomenon or research question?
- Will the research, if successful, make a difference to the people, leadership and systems affected by health emergencies and disasters?
- Why are you and your team well suited to study this problem?

Focusing your research interests can give a young researcher an opportunity to master specific research domains, tools, methods, and to become familiar with pertinent networks and resources. However, this is also a delicate balance – it is best to avoid too narrow a focus early on in a young researcher's career, but young researchers should also avoid being a "jack of all trades".

In order to secure funding, academic positions, employment or promotion, a young researcher will often have to describe their passion for their research interests and demonstrate refined skills in a specific area of interest such as being facile in using quantitative, qualitative or data mining methods *(13)*. It is often easy to identify a clear research focus in "successful" researchers. Initial steps, such as reading senior faculty's researcher profiles, reviewing their abstracts and published manuscripts, drilling down into earlier successive papers from the same researcher or research team, and writing and sharing drafts of research interests can help young researchers gain valuable insights into the academic ideation, and implementation process.

Reading existing articles on related topics will advance your knowledge on the topic and help you to critically interpret other researchers' findings, even and especially if they are negative reviews. Furthermore, immersing oneself in clinical encounters will trigger you to think about ideas for new studies, and help you to understand when others have found answers, so that you do not replicate existing studies. Most journals of merit will decline your studies if they are merely copies of earlier studies.

Some formal training in research methods, either quantitative or qualitative, is essential, and will give you an added advantage to complement your content expertise. Mastering the important concepts discussed elsewhere in this book, such as the formulation of a research question (Chapter 3.5), study design (Section 4), basic descriptive and analytical statistics (Chapter 4.2), sources of bias and research ethics (Chapters 3.4 and 6.4) can often make the difference between publishable manuscripts and fatally flawed ones *(14-16)*. More importantly, poorly designed and conducted research studies might jeopardize a young researcher's reputation and self-confidence, the safety of participants in the research, the possibility to acquire more funds in the future and the reputation of their institution *(17)*. This often results in wasting of limited resources. Young researchers are invited to consider all the available options, such as short courses on grant writing, online resources, and formal degrees. Within institutions, young researchers can organize journal clubs, and widely read and share their critical assessments with each other of their research and how best to learn from one another's work.

### 6.1.5 Start writing early

The penultimate outcome of research is a published scientific publication in a reputable peer review journal, that has potential for public health impact. The original findings can be shared, judged and used to improve practice and policy. Strong and clear-eyed writing skills are important for successfully achieving grant funding (Chapter 6.3) or peer review publications (Chapter 6.7) and will contribute to career development and success milestones *(18)*. Mastery of the skills required for prolific authorship (including language accuracy, technical accuracy, structured discourse and conciseness) needs to be acquired early. It is essential to learn to formulate a hypothesis and the aims of your study; to learn about different article outcomes; and to learn how to do an expert literature search and review. It is unlikely that you can acquire all the skills required for scientific writing without a lot of practice – hence the earlier a young researcher experiences the hurdles and workload involved in manuscript preparation, the better. Learning to work "smart" with realistic planning and efficient time management will go far, even if you spend only 15 minutes a day refining your work *(19)*. Learning how to deal with and plan for research and grant deadlines is essential. Presenting your research outcomes to your team, your immediate colleagues and perhaps to a wider group of colleagues at conferences – and being receptive to criticisms even when delivered in a critical manner – can be remarkably beneficial and humbling.

When you choose an important but highly complex problem, remember to break it down into digestible parts and build your research competencies one study at a time. First-hand experience with manuscript formatting, referencing, determining authorship, reporting data, grant reviewing, and undergoing peer review are important steps towards an independent career in research. Discuss your proposal with as many people as possible before you start to write to ensure that you have a solid experimental design.

Finally, finding which grants are applicable for your research focus, and being prepared in time for deadlines are battles that will push your limits no matter how wonderful and experienced your supervisors. It is inevitable that one's respect for those who have gone before will grow with each and every passing day.

## 6.1.6 Doing action research in the field

Strive to do active field research as early and often as you can because this will greatly deepen your understanding of the workflow, enrich your sense of accomplishment and grow your career. Evaluating Health EDRM interventions is critical, while helping you to build rapport and respect with disaster and risk management clinicians and policy makers*(20)*. As you refine your research focus and start to design your research study, you should reflect on the guidance elsewhere in this book. This includes obtaining the necessary funding (Chapter 6.3) and ethical approval (Chapter 6.4) and planning to do the research in the field (Chapter 6.5). Doing field research will help you to learn more about a variety of issues described next, as well as improving your knowledge of practice in the field.

**Overcoming lack of data**
Field research can resolve gaps in data. Very often, there is limited to no data about a chosen study topic, especially in a specific environment, such as in trying to assess the pattern of a disease outbreak – the problem might be known or suspected, but there is no way to validate your assumptions without primary data. Conducting field research not only helps plug gaps in data and your understanding of the problem, but also helps with the collection of supporting material, such as the availability of suitable drugs and equipment for emergency care and information about how decisions are made under real world constraints *(21)*.

**Understanding the context of the study**
In many cases, field research supplements other data and can help you better frame the research question (Chapter 3.5). This can provide insights into the existing data but also into the culture and the workflow context of the people working in the field, such as how healthcare systems actually behave when stressed during a tsunami *(22)*. For example, if the data states that clinicians can easily perform emergency intravenous resuscitation while wearing a hazmat suit because the clinicians are well trained *(23)*, field research might identify other factors that influence the success of and barriers to successful donning of disaster hazmat suits. In depth ethnographic observations for example, can help the researcher to avoid preconception bias with regard to fit and comfort, reading and operating equipment, hearing and communicating, reaching and moving, and dexterity to use touch screens, press buttons, open vials/taps and use of syringes. These might also include the fogging up of their glasses, the lack of full proprioception of their gloved hands, the impact of distracting human factors elements such as noise, harsh weather and the subjective personal danger and anxiety of the treating clinicians under adverse conditions *(24)*.

**Increasing the quality of data using mixed methods**
Since field research usually uses more than one tool to collect data, mixed methods data will be richer and of higher quality *(25)*. This might allow you to harvest more meaning from the data *(26)*. Inferences can be made from the data collected and triangulation of multiple methods (Chapter 4.13) can be used in the analyses to help to overcome the small sample sizes or incomplete data description *(27)*.

**Collecting ancillary data**
Collecting field research data puts you in a position of localized thinking, which opens you to new lines of inquiry and understanding of the phenomenon and can help avoid getting locked into groupthink. This can help you better appreciate and more critically review existing published articles while using the rich nature of mixed methods data sources to address the challenges of variable data sizes and levels of robustness *(28-29)*.

**Applying the data to real world clinical risk management and disaster service care**
It is key to appreciate the workflow and work processes of frontline emergency, disaster workers and managers in order to better evaluate the impact of emergency service delivery interventions and how best to modify and improve them *(30-31)*. This applied work can help you to reconcile the rich quantitative and qualitative traditions and methods as you strive to anticipate and support the needs of frontline health care workers in improving patient care under real world demands and resources *(32)*.

### 6.1.7 Find an expert and nurturing mentor

Perhaps the most important predictor of your success as a researcher will be your ability to find the right mentors. It is important to distinguish between a supervisor and a mentor. A mentor is a wise, confident and trusted counselor or teacher, someone who enthuses you, and has your best interest at heart. Supervisory roles are often limited in time and commitment, usually leading to distinct academic outcomes or professional goals. On the other hand, a mentor and mentee can negotiate their expectations and goals and use a wide variety of skill transfer techniques to achieve them, often for extended periods. The benefits of mentoring have been reported to be associated with a wide range of favourable behavioural, attitudinal, health-related, relational, motivational and career outcomes *(33)*. They also include a greater likelihood of publishing, better academic and career growth, higher research productivity, and a genuine opportunity to learn skills that cannot be achieved through formal channels *(34)*. Today, with improved communication facilities, a young researcher can expand their pool of potential mentors to distant geographic regions globally. In addition to the direct knowledge transfer that occurs between a mentor and a mentee, the mentor can also introduce the mentee to a wider network of collaborators in different disciplines. Reverse mentoring adds great value to the mentor by helping senior mentors learn about various new topics of strategic, technical and cultural relevance.

Mentorship is not without drawbacks, and it is crucial to establish a mechanism to determine when such relationships are not working well.

Mentees can be taken advantage of however, including when their ideas or funding are usurped. At times, these relationships can be fraught with tension, competition and difficult dynamics given the uneven power hierarchy. Always look for mentors who are known to be generous and honest with their mentees, have high integrity and enjoy mentoring. Such people do things not out of selfish gain, but for the good of science and to support the people being mentored first and foremost. They educate rather than give orders, leaving the final decisions to the mentee. Consider publications of potential mentors to ascertain that they consistently support their trainees to be first authors and present key scientific output at conferences.

When you find someone who has heart, expertise, and the right personality, let them know you want to be successful in medical research just like them and that you would like to be mentored by them. But remember this truth: mentorship is a two-way process. You must commit to the hard work and show your dedication, learning from each interaction and never taking your mentor's valuable time for granted. A mentor teaches you but you must demonstrate that you are applying what they taught you if you are to succeed. Make sure to keep a log of all your meetings with your mentor and learn to prepare a summary memo that will enshrine what was discussed and help to hold you and your mentor to the agreed upon meeting actions. This will demonstrate to your mentor your ability and maturity as a budding colleague.

### 6.1.8 Conclusions

A successful career in biomedical research can be an exciting life choice that can add a special extra meaningful dimension to your professional career and life. Seek out work on important problems – problems that truly matter to you – and choose to study research topics that can make a difference to patients, their families, society and humanity. Strive to work, and surround yourself with people who are smart, courageous and curious. You want to work with the right people and at the right university, healthcare system, non-governmental organizations or international institutions, such as WHO or the United States Agency for International Development. In doing so, you will be inspired by this work, by the people who need help and by those trying to help them.

Research and academic studies are both challenging and time consuming, so seek out research problems about which you are passionate about. Good academic research is hard and daunting; it becomes more so without genuine passion for the subject matter. You need to be passionate about your research if you are to negotiate the challenges that lie ahead, and as you live through the inevitable days of grant and research frustration and disappointment. Learn to savour the small wins and celebrate the findings and joy that come with being able to help reduce pain and suffering while seeking to understand and master the mysteries of the world.

### 6.1.9 Key messages

- **Research can be exciting, rewarding and innovative, improve the evidence of policies, reduce uncertainties and lead to improvements in patient care, practice and policy.**
- **Formal education is the foundation of a career as a researcher, but other key skills and practical training are vital too – such as refining your critical thinking and problem solving abilities, a strong work ethic, good project management and communication skills, and being receptive to feedback.**
- **It is important to establish your research interests. Ask yourself: Why is this research needed now? Who cares about this phenomenon or research question? Will the research, if successful, make a difference to the people and systems affected by health emergencies and disasters? Why are you and your team well suited to study this problem?**
- **Research projects should be scientifically sound and guided by ethical principles in all their aspects.**
- **Doing research in the field can help to plug gaps in the data, improve data quality and provide ancillary data, and also give you and your research team a more nuanced understanding of the real-world context of a problem and potential suitability of proposed solutions.**
- **Finding the right mentor is essential and can be instrumental to a researcher's career success.**
- **Research implementation is essential and while it may seem straightforward requires careful advanced planning, multiple stakeholder involvement, addressing other contextual constraints to increase chances for programme stickiness, scale up success and sustainability.**
- **The best research consists of an iterative process of learning, is typically incremental, and is constantly being infused by everyday work experience and hard-earned lessons by researchers working closely with frontline clinicians and staff to provide exceptional, high quality and patient centered clinical care.**

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# 6.2

# How to identify and access reports of existing research

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## 6.2.1 Learning objectives

To understand the key factors to consider when searching for evidence for Health EDRM, by:

1. Recognizing the issues related to searching for evidence for Health EDRM;
2. Understanding the techniques required for finding the best evidence for Health EDRM;
3. Identifying relevant information sources to answer the focused question; and
4. Being aware of how to manage and appraise the evidence retrieved, so that it can be applied in practice.

## 6.2.2 Introduction

"Effective healthcare response requires evidence and information to meet various and often unpredictable eventualities" *(1)*. Making good health decisions requires combining the best available research evidence with relevant knowledge and experience, and matching it to local context – which is particularly important in areas where the situation is uncertain, such as in disaster zones and when working on Health EDRM. Information overload is a daily reality for all health practitioners as they struggle to cope, not only with the volume of published literature, but also with the ever-increasing digital exchange from a wide range of sources, and of variable quality.

As shown elsewhere in this book, problems of quality can arise from poor research design and reporting biases but the way evidence is reported, published and organized can also contribute to problems such as difficulties in finding it in bibliographic databases (see below) or lack of open access *(2)*. Perceived lack of time and limited skills in finding and using online resources also contribute to unsystematic and unsuccessful methods of information retrieval, leading the practitioner to consider that 'finding the evidence' represents a significant barrier to evidence-based practice. Good evidence is available, but to find it effectively, practitioners need to acquire knowledge and skills: knowledge about the range, quality and content of available sources of evidence, and the skills to use these sources effectively. This chapter aims to help you to achieve this. It complements Chapter 2.6, which discusses the role of systematic reviews as a source of evidence, and Chapter 3.7, which describes specific collated resources, such as that created by Evidence Aid *(3)*.

This chapter is intended to help you build skills in finding the evidence you need in a global and disaster health context, by raising your awareness of the range of information sources available, and demonstrating how a structured approach to building search strategies can improve results. These skills should help you to find evidence that will help you to make well-informed decisions about practice and policy, and also to ensure that any research you design, conduct and report takes proper account of other similar studies, as discussed in Chapter 3.5.

## 6.2.3 Searching for global and disaster health evidence: Key issues

There are different types of disaster (Chapter 3.2):

**Natural**: earthquakes, landslides, tsunamis, windstorms, extreme temperatures, floods, droughts, or wildfires.

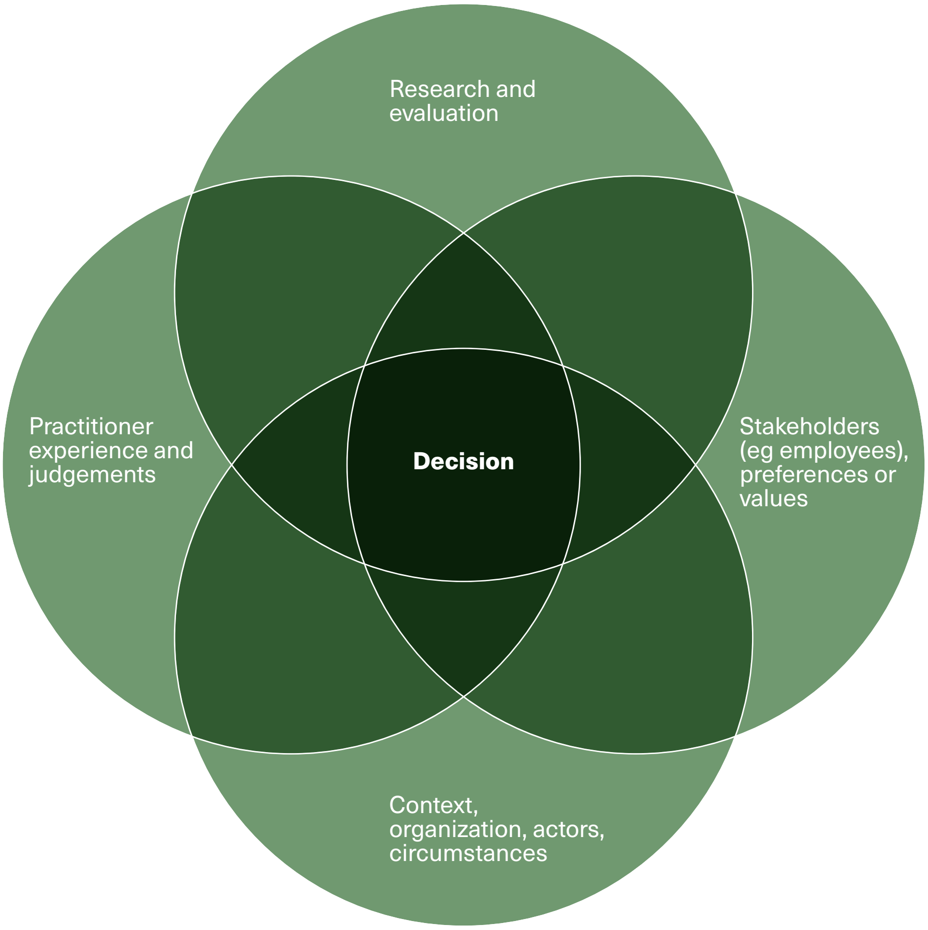
**Biological:** disease outbreaks, including human, animal, and plant epidemics and pandemics.

**Technological:** chemical and radiological agent release, explosions, and transport and infrastructure failures.

**Societal:** conflict, stampedes, acts of terrorism, migration, humanitarian emergencies, and riots.

Figure 6.2.1 illustrates the concepts of evidence-informed decision-making in public health, which would also apply to disasters more specifically *(4)*. In terms of global and disaster health, the context, organization, actors, circumstances (which might include power disruptions resulting in limited or no Internet access), time constraints, cultural issues, safety, local priorities and vulnerabilities, and literacy levels of the community are all important. Furthermore, during emergency situations, there is often a significant burden of disease and limited resources for rescue teams to work with *(5)*.

**Figure 6.2.1 Evidence-informed decision making in public health** *(4)*



Finding evidence for Health EDRM requires an awareness of – and ability to retrieve – relevant studies from a wide range of primary and secondary sources across multiple disciplines. These often use differing terminologies and indexing techniques, adding to the complexity of searching for evidence in this field.

## 6.2.4 Introduction to searching

Developing a systematic and reproducible approach will help you retrieve the most relevant results, save time, and avoid missing important material. Searching techniques need to be *sensitive* (to get as much relevant information as possible) and *specific* (to minimize the amount of irrelevant information retrieved).

**Formulating a searchable question**
When searching the literature, it is essential to construct a focused question, so that there is no ambiguity around what is being searched for. There are several frameworks *(6-7)* that can be used to help turn the scenario into a focused question, and identify relevant terms on which to base the strategy and words that mean the same (synonyms). Table 6.2.1 lists some of these frameworks.

### Table 6.2.1 Frameworks for formulating searchable questions

| Framework | Definition | Area of interest |
|---|---|---|
| PICO | Patient/Problem/Population, Intervention, Comparison, Outcome | Clinical interventions |
| PECOT | Patient/Problem/Population, Exposure, Comparison, Outcome, Time | Causation or prognosis |
| SPICE | Setting, Perspective/Population, Intervention, Comparison, Evaluation | Project, service or intervention evaluation |
| SPIDER | Sample, Phenomenon of Interest, Design, Evaluation, Research type | Qualitative or mixed methods |
| ECLIPSE | Expectation, Client group, Location, Impact, Professionals, Service | Service evaluation |

A framework does not have to be applied, but it is important to break the scenario into concepts or themes, so that it is clear what is being searched for. Three or four concepts should help you to find relevant evidence, but sometimes, the answer can be found by searching for just two concepts. Four concepts to consider are:

**Concept 1** – could be the key population and/or setting

**Concept 2** – might be the type of intervention or exposure

**Concept 3** – perhaps a comparison of a second intervention

**Concept 4** – refers to the final, expected outcomes.

For example, consider the question “What is the evidence on communicable disease and infection control in areas of conflict?” There are three main concepts in this – communicable disease, infection control, and areas of conflict – and the search must find reports about all of these concepts. Under each of the concepts, consider all the alternative terms that could apply to that original concept (Table 6.2.2). For articles in English, think about both American and British terminology and spellings, or brand names. For example, tsunamis are also known as harbour waves, harbor waves, or tidal waves, and earthquakes, as quakes, tremors, or temblors.

### Table 6.2.2 Example of building search using term concepts

| Concept 1: Communicable disease | Concept 2: Infection control | Concept 3: Areas of conflict |
|---|---|---|
| infection | prevention | war zones |
| infectious disease | prophylaxis | emergencies |
| Zika | prophylactic | disasters |
| Ebola | antibiotic chemoprophylaxis | relief work |
| cholera | | rescue work |
| dengue fever | | humanitarian crisis |
| plague | | |

If you already know of, or can find a report that covers the topic that you are interested in, looking at the key words and phrases used in it and those used to index it may help you identify additional search terms.

### 6.2.5 Step-by-step guide to searching bibliographic databases

If the reports you are interested in have been published in scientific journals, these might be available through electronic bibliographic databases. These include, for instance, PubMed for health care, Global Index Medicus for regional health research, and ERIC for educational literature. These are all freely available. There are also some useful, subscription-based resources, including Embase, which includes conference abstracts and journals that are not indexed on PubMed; Scopus; and Web of Science. If possible, working with a librarian or information specialist should help you to decide which of the many hundreds of such databases to search. Some of the databases are restricted to simple searching, where only the words entered will be searched for. Some allow advanced searching, where it is possible to limit the search to particular parts of each record (fields), such as the title and abstract.

These next paragraphs describe the general principles for searching, and they apply to most databases, but some may operate differently. For example, the truncation and wildcard symbols differ across databases or database vendors (such as OVID). The Help facility for each database can provide details of any differences and provide the best advice for searching effectively. Universities are a good source of useful guides to database searching, for example McMaster University, which provides searching guidance on a range of topics (8). Where possible, it may save you time to engage the services of a librarian or information specialist, who will have the skills to conduct an effective search. There are also discussion forums that might be helpful for finding advice from topic experts (see Table 6.2.5).

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#### Thesaurus searching

More complex databases will provide access to a thesaurus (also known as index, MeSH or subject headings) where every article that is added to the database is tagged with a set of index terms, to help retrieve articles specifically on that topic. If a thesaurus is available, this is the best place to start searching, because the references found should be highly relevant. When the thesaurus term is selected, there will be an option to "explode" results ("exp") so that the term you entered and any narrower thesaurus terms will be included. For a comprehensive search, it may be best to initially explode terms, and then narrow down the search by combining with the other concepts. However, if the search is retrieving too many irrelevant results, then going back to that term and de-selecting the "explode" option so that it only searches for that one index term and none of the narrower terms may help remedy this.There is sometimes an option to choose a "major topic" or "focus", but these can be too restrictive because they will focus more on that chosen term. Once the thesaurus term is selected, there is an option to narrow down by "subheading". Again, it is good practice to keep the search broad, and include all subheadings, but if time is of the essence, the subheadings are a useful tool to reduce the number of records retrieved and increase the concentration of the most relevant records. For example, there are subheadings for prevention and control, therapy, diagnosis, and causality, among others, so it is possible to be more specific in the search. However, this focusing down by using subheadings runs the risk that key papers will be missed because they have not been assigned the relevant subheading.

The thesaurus terms include synonyms related to that term. However, you need to be cautious because it can take a few months for index terms to be added to a new record, which means that a reliance on these terms alone will miss the most recent reports that have not yet been tagged.

**Free text searching**

Once the thesaurus terms have been searched, a free text (also known as natural language or keyword) search can be conducted. The database will search the whole content of each record in the database (but not the article's full text), for the term that has been entered and no other variations. It will not look for similar terms, plurals, or spelling variations. Truncation, such as * and $, and wildcards, sometimes signified by a ?, help to improve retrieval by expanding options. For example, prophyla* will look for prophylaxis or prophylactic, while behavio?r will retrieve papers containing the British and American spellings. However, not all databases use the same methods of truncating. Searchers should refer to the "help page" or "search guides" for each database so that they can apply the correct methods to do free text searching in that resource.

**Proximity searching**

This technique is a way of combining words, so that they are searched for in close proximity to each other. This helps to yield more relevant results. NEAR or N and ADJ are the most commonly used proximity operators. ADJ specifies that the terms appear in the order required, while NEAR lets the terms appear in any order. When numbers appear after the word, it means that the terms are separated by that number of words. For example, primary ADJ2 care will find articles on primary care or primary health care; while disaster N2 manag* or disaster NEAR2 manag* would retrieve papers on disaster management or management of disasters or managing disasters. However, not all databases allow proximity searching, and therefore, searchers should refer to the "help page" or "search guides" for each database to understand the most effective way to do free text searching in that resource. However, not all databases allow proximity searching, and therefore, searchers should refer to the "help page" or "search guides" for each database to understand the most effective way to do free text searching in that resource.

**Combining searches**

For comprehensive results, it is necessary to search for each concept, one at a time, combining with OR within each concept. The search string for each concept can then be combined using AND, so that the reports retrieved contain all the concept terms and/or synonyms.

**Table 6.2.3 Combining search terms**

| Concept 1: | | Concept 2: | | Concept 3: |
|---|---|---|---|---|
| **communicable disease**<br>**OR** infection<br>**OR** infectious disease<br>**OR** zika<br>**OR** ebola<br>**OR** cholera<br>**OR** dengue fever<br>**OR** plague<br>**OR** disease outbreaks | **AND** | **infection control**<br>**OR** prevention<br>**OR** prophylaxis<br>**OR** prophylactic<br>**OR** antibiotic chemoprophylaxis | **AND** | **areas of conflict**<br>**OR** war zones<br>**OR** emergencies<br>**OR** disasters<br>**OR** relief work<br>**OR** rescue work<br>**OR** humanitarian crisis |

When you are doing your initial search, start with something broad, or sensitive. This will find a lot of material, much of which may not be relevant but it is important not to limit or narrow the search too early, because this may exclude vital evidence from your search results. Once you have entered all the terms you wish to use, the overall results can be limited by a range of options, to suit the population or question you are interested in. Types of limits include:

- language of article;
- date of publication;
- age of population;
- publication type (that is, to restrict to specific research methods including randomized controlled trial, meta-analysis or systematic review).

Methodological search filters *(9-11)* are pre-tested literature search strategies that provide a more effective way of refining a search to find evidence appropriate to the type of question under investigation. They may be designed to maximize sensitivity (or recall) or to maximize precision (and reduce the number of irrelevant records that need to be assessed for relevance). Many databases have these filters built in and available for application at the limiting stage.

Table 6.2.4 contains an example of a comprehensive database search. The number of results for each term are in brackets and you can see how the numbers end up as a much more manageable figure by the end of the search.

## Table 6.2.4 Example of a search strategy

| | |
|---|---|
| 1 | exp Communicable Diseases/ (33764) |
| 2 | exp Disease Outbreaks/ (88997) |
| 3 | exp Infection/ (757664) |
| 4 | infectious disease*.tw. (71286) |
| 5 | exp Zika Virus Infection/ (3163) |
| 6 | exp Hemorrhagic Fever, Ebola/ (4822) |
| 7 | exp Cholera/ (8422) |
| 8 | exp Dengue Virus/ (8141) |
| 9 | dengue fever.tw. (4273) |
| 10 | exp Plague/ (5060) |
| 11 | or/1-10 (901566) |
| 12 | exp Infection Control/ (60674) |
| 13 | exp Primary Prevention/ (144184) |
| 14 | prevention.tw. (497908) |
| 15 | prophyla*.tw. (154455) |
| 16 | antibiotic chemoprophylaxis.tw. (53) |
| 17 | or/12-16 (805099) |
| 18 | area* of conflict.tw. (255) |
| 19 | exp Warfare/ (36098) |
| 20 | war zone*.tw. (556) |
| 21 | exp Emergencies/ (39087) |
| 22 | exp Disasters/ (81001) |
| 23 | exp Relief Work/ (4663) |
| 24 | exp Rescue Work/ (2039) |
| 25 | (humanitarian adj (crisis or crises or effort*)).tw. (409) |
| 26 | or/18-25 (115660) |
| 27 | 11 and 17 and 26 (1183) |
| 28 | limit 27 to (English language and last 5 years) (176) |

**Key:** exp – explode term; tw – only searches in the title and abstract fields; adj – adjacent and refers to proximity searching

If too few results are retrieved, then these should be reviewed, and if there are any papers that are exactly as required, these should be checked to see if they contain terms that you might add to your search strategy. If there are, these terms should be added and the search run again to identify other similar reports that were missed the first time.

**Methods for refining searches**
Search filters are specially designed search strategies for different databases, which retrieve records on different themes, such as particular study type, geographical location, age, population group, etc.

The InterTASC Information Specialists' Sub-Group Search Filter Resource provides easy access to published and unpublished search filters.
https://sites.google.com/a/york.ac.uk/issg-search-filters-resource/home

In addition to these, the Cochrane Effective Practice and Organisation of Care group has developed a set of filters for PubMed (NLM), MEDLINE (Ovid), Embase (Ovid), and CENTRAL (Cochrane Library) to help identify studies relevant to low- and middle-income countries (LMICs). Please note: The Cochrane EPOC filters have not been tested for sensitivity and precision.
https://epoc.cochrane.org/lmic-filters

### 6.2.6 Saving your search strategy

Most databases have the option to save the search strategy for future use, and some allow the strategy to be saved as an "alert", so that when new reports that match the search strategy are added to the database, a message is emailed to you. It is important to save a copy of the search strategy along with the date of the search, particularly if the results are to be shared with colleagues or across agencies. This allows someone else to re-run the search later, without having to revisit earlier results. Searching the scientific literature is an iterative process, and strategies may need to be refined and re-assessed throughout the process to improve relevance and ensure that results can be recorded and stored appropriately.

### 6.2.7 Other searching techniques

Much of this chapter has focused on database searching, but there are other techniques that can be applied:

- **Citation searching** – looking up a specific report in a citation index, for example Web of Science or Scopus, to see who has cited it, and then who has cited their work, and so on.
- **Reference list checking** – identifying additional relevant references and terms by looking at the reference list of a key paper that strongly relates to your question *(12)*.
- **Contact with experts** – getting in touch with the authors of relevant reports to see if they have other work in the pipeline or if they can recommend other experts who have published on the topic.
- **Text mining** – refers to the automated analysis of large collections of written content to identify additional terms to include in the search *(13)*.
- **Pearl harvesting** – taking one reference, and using the terms applied to it to identify additional terms for the search strategy *(14)*.

### 6.2.8 Key sources of evidence

It is crucial to choose appropriate information sources to search – that is, sources that are likely to contain the type of evidence required. For articles in scientific journals, this is likely to focus on bibliographic databases but you may need to search other sources as well. Grey literature are non-conventional publications, which include conference proceedings, local guidelines, dissertations, bibliographies, technical reports, unpublished official documents and so on (Chapter 3.6) *(15)*. Grey literature is a valuable source of information because it can provide important data about the local context.

As discussed in Chapter 2.6, up-to-date systematic reviews or evidence syntheses that have tackled your question might allow you to move quickly to an answer. When time is of the essence, there may not be time to find and read the full reports of many studies, and so especially in emergency situations, evidence syntheses are essential as they highlight the key messages needed to make quick and accurate decisions. However, the recommendations that are made in such evidence syntheses may not always be feasible in disaster zones. For example, you may not have access to the medication or equipment that research elsewhere has shown to be most effective. Even if you can find a systematic review in your general search or can access collections such as those discussed in Chapter 3.7, you will still need to consider its relevance to your setting and whether you need to supplement it with searches for additional context-specific research. Table 6.2.5 introduces a collection of information sources, organized by levels of evidence. This list is not comprehensive and other information sources are available. A librarian or information specialist can help identify alternative information sources pertinent to your requirements.

**Table 6.2.5 Hierarchy of searching for global and disaster health**

**Guidelines:**

*Medbox: The aid library*
This is an open source library for health-related work, humanitarian action and development assistance. It contains key information on Ebola, Zika, Tuberculosis, Cholera, Leprosy, Polio, natural hazards, conflict, rapid response, refugee, disability, and specific hazards.
www.medbox.org.

*Medécins Sans Frontiéres*
This collection of medical guides has been produced to help people working in areas with epidemics of infectious disease, and emergency situations.
https://medicalguidelines.msf.org/viewport/MG/en/guidelines-16681097.html

*Oxfam GB Guidelines and toolkits*
Oxfam publishes a range of resources, including guidelines, manuals and training packs that provide advice and tools for practical application and adaptation. These cover many different thematic areas including, gender justice, livelihoods, private sector engagement, climate change, resilience, humanitarian response, water and sanitation, governance and fragile contexts.
policy-practice.oxfam.org.uk/our-approach/toolkits-and-guidelines.

*TRIP (Turning Research Into Practice)*
TRIP searches a range of health information sources to inform clinical and non-clinical decision-making. It contains all levels of evidence, and the results are delivered with the highest level of evidence first. This is free to access, but an enhanced version, TRIP Pro, is also available free to countries with low resource. www.tripdatabase.com.

*WHO: Emergency surgical care in disaster situations*
These guidelines have been extracted from the WHO manual Surgical Care at the District Hospital (SCDH), which is a part of the WHO Integrated Management on Emergency and Essential Surgical Care (IMEESC) tool kit.
www.who.int/surgery/publications/s16368e.pdf.

**Evidence maps and syntheses *(see also Chapter 2.7)*:**

*Humanitarian Evaluation, Learning and Performance (HELP)*
This resource contains almost 17 000 resources to support evaluation, learning and performance in the humanitarian sector. www.alnap.org/help-library.

*International Initiative for Impact Evaluation (3ie)*
3ie produce briefs which summarize evidence from 3ie-supported impact evaluations, systematic reviews, replications and evidence gap maps. They also include summaries of their research programmes, lessons from grant making and instances of uptake and use of evidence. Their database also includes systematic reviews of the effectiveness of social and economic interventions in low- and middle- income countries. It contains almost 303 summaries of systematic reviews drawn from a range of sources and sectors.
www.3ieimpact.org/evidence-hub/publications/briefs/.

### Systematic reviews *(see also Chapter 2.7)*:

*Campbell Collaboration*
This database contains systematic reviews on the effects of interventions in crime and justice, education, international development, and social welfare. campbellcollaboration.org.

*Cochrane Library*
This is a collection of databases that contain different types of high-quality, independent evidence to inform healthcare decision-making. It is also available as a Spanish language version (cochranelibrary.com/es/home). https://www.cochranelibrary.com/

*PROSPERO: International prospective register of systematic reviews*
This is a register of protocols for systematic reviews, rapid reviews, and umbrella reviews. It should be searched before undertaking a review, to avoid duplication of effort and wastage. www.crd.york.ac.uk/prospero/

*Evidence Aid*
Evidence Aid, along with partners (including the International Rescue Committee (USA) and Cochrane), has assessed published systematic reviews. Those identified as being of relevance to natural disasters, humanitarian crises or major healthcare emergencies, that include health outcomes, are included within the four categories and include a summary of the review before it links to the full article. Most summaries are also available in Spanish and French. www.evidenceaid.org/resources/

*PubMed Clinical Queries*
The resource is designed to filter PubMed records by three clinical research areas: Clinical Study Categories (diagnosis, therapy, prognosis and so on), Systematic Reviews, and Medical Genetics. www.ncbi.nlm.nih.gov/pubmed/clinical.

### Primary research

*Global Index Medicus*
This is a collection of the Regional Index Medicus, and contains medical and health documentation from low-income countries, outside the major industrialized areas.
search.bvsalud.org/gim/advanced.

*PubMed*
PubMed is a database containing more than 30 million citations from biomedical literature, journals, and online books. www.pubmed.gov.

### Clinical trials

*International Clinical Trials Registry Platform (ICTRP) search portal*
The World Health Organization's portal is a searchable database, which aims to provide a single point of access to information about ongoing and completed clinical trials. This site also includes links to trial registeries from other countries, including China, Netherlands, Germany, Japan, the Republic of Korea, Persia, Peru, Portugal, and the Kingdom of Spain.
www.who.int/clinical-trials-registry-platform

## Grey literature

*EM-DAT: The International Disaster Database (see Chapter 2.1)*
This resource provides information on the human impact of disasters - such as the number of people killed, injured or affected, along with disaster-related economic damage estimates and disaster-specific international aid contributions. www.emdat.be/publications.

*Prevention Web*
This is a collaborative knowledge-sharing platform on DRR, managed by the UN Office for Disaster Risk Reduction (UNISDR). It contains a range of knowledge products and services to facilitate the work of DRR professionals. www.preventionweb.net/english/.

*Relief Web*
This is a humanitarian information source on global crises and disasters, and provides reliable and timely information, including the latest reports, maps and infographics from trusted sources, enabling humanitarian workers to make informed decisions and to plan effective response.
reliefweb.int.

*Resilience Library – South East Asia Resources*
The International Federation of Red Cross and Red Crescent Societies has collated information on the following topics: climate change, communication and advocacy, disaster law, disaster risk reduction, gender and diversity, health, migration, national society development, and youth and volunteering.
www.rcrc-resilience-southeastasia.org.

*Environment, Conflict and Cooperation (ECC) Platform Library*
This resource contains documents on topics, including climate change, environment and migration, early warning and risk analysis, and conflict transformation.
library.ecc-platform.org.

*TRACIE Healthcare Emergency Preparedness Information Gateway*
This resource is produced by the US Department of Health & Human Services. It was created to meet the information and technical assistance needs of people working in disaster medicine, healthcare system preparedness, and public health emergency preparedness.
https://asprtracie.hhs.gov/

## Discussion forums

*Healthcare Information for All (HIFA)*
Healthcare Information for All is a global health network with more than 18 000 members (health workers, librarians, publishers, researchers, policymakers) committed to the progressive realization of a world where every person has access to the healthcare information they need to protect their own health and the health of others. Its members have a vast and unique experience and expertise which they can use to bring clarity to challenging questions around global health issues in general and healthcare information issues in particular. www.hifa.org.

*Disaster Outreach Librarians*
This is a discussion list where topics related to library services and disaster preparedness can be discussed, and experiences shared.
disasterinfo.nlm.nih.gov/dimrc/dimrclistserv.html.

## Tools

*Disaster apps for your digital go bag*
The apps on this page contain information to support disaster management, including dealing with blast injuries, hazardous material and incident response and planning, radiation and nuclear emergencies, etc. They have been designed to provide mobile device users access to web-based content, and run on specific mobile platforms, such as iOS (iPhone and iPad), Android, or Blackberry. disasterinfo.nlm.nih.gov/apps.

**Google and Google Scholar**

Google (https://www.google.com/) is easily accessible, and can identify relevant information, particularly when a topic is new, and there is not yet much established literature. It is also useful for finding news items, videos and pictures, grey literature, and information about specific organizations.

Google Scholar (https://scholar.google.com/) can be used to quickly locate research papers, particularly full-text articles, but it is not easy, or comprehensive, to use for complex searches.

*The International Federation of Library Associations and Institutions (IFLA) Evidence for Global and Disaster Health* (E4GDH) has produced two guides, linking to many more information sources: finding the evidence for global and disaster health. www.ifla.org/publications/node/81736?og=25692.

### 6.2.9 Managing references and creating bibliographies

As your collection of reports grows, you may find it helpful to use reference management software for managing the citations, formatting them into standard referencing styles (such as Harvard, Vancouver and so on), making annotations, and sharing collections with colleagues to facilitate collaborative working across agencies. Endnote (endnote.com) is a subscription-based reference management software, but it does have a component called Endnote Basic (http://myendnoteweb.com), which is a basic free online version that can be used as a stand-alone or together with the subscription-based version of desktop Endnote.

### 6.2.10 Transparent reporting

When writing research reports, it is important to demonstrate that your methodologies are transparent and robust, and there are a range of tools and standards available to help with this.

The EQUATOR Network (Enhancing the QUAlity and Transparency Of health Research (www.equator-network.org/)) seeks to improve the reliability and value of published health research literature by promoting transparent and accurate reporting. The network has produced 463 reporting guidelines for the main study types, including randomised trials, observational studies, systematic reviews, and economic evaluations. These tools can be used to record the number of included and excluded papers at each stage of the research process.

### 6.2.11 Obtaining the full text of reports

Databases will provide brief summaries of the reports, known as abstracts, and in some cases, will include a link to the full text. If this is not the case, there are some options available:

- Local librarian – libraries often have access to a range of other libraries and can source reports this way.
- Direct links from the database – if access to the full text is available, either via your local subscription or open access, these will link directly to the journal publisher.
- Open access databases – PubMed Central is a database which provides access to open access reports (www.ncbi.nlm.nih.gov/pmc).
- HINARI– was set up by WHO together with major publishers to enable people in low- and middle-income countries to gain access to one of the world's largest collections of biomedical and health literature. Visit the website to see eligibility criteria (www.who.int/hinari/en).
- Emergency Access Initiative (EAI) – provides temporary, free access to full text articles from major biomedicine titles to healthcare professionals, librarians, and the public affected by disasters in a region of the USA or throughout the world. This site is only active when a disaster event is named and the access period specified. Visit the website to see eligibility criteria (eai.nlm.nih.gov).

### 6.2.12 Appraising the evidence

Critical appraisal is the process of assessing and interpreting evidence, enabling you to systematically assess the trustworthiness, relevance and results of published papers. There are many useful tools and checklists to help appraise retrieved content. A simple checklist to assess whether the information is relevant and reliable is:

- **Authorship** – Who wrote the content and what are their credentials? Are they qualified to provide this information?
- **Attribution** – is it clear how the information was generated (for example, is it referenced)?
- **Disclosure** – is the website sponsored by anyone who might have a commercial gain? When did they write it? Who did they write it for?
- **Currency** – is there a date to indicate age of the content? *(16)*

The Critical Appraisal Skills Programme has a set of eight critical appraisal tools, which can be used to assess the quality of research papers (casp-uk.net/casp-tools-checklists/). The Centre for Evidence Based Medicine has translations of some of these English language checklists – into Chinese, German, Lithuanian, Portuguese, Spanish, and Persian (www.cebm.net/2014/06/critical-appraisal/).

### 6.2.13 Conclusions

Finding the evidence to inform decisions can be challenging in Health EDRM, particularly when timescales are short, and situations are resource-poor. This chapter provides guidance on searching for this type of evidence, so that people working in these areas can make informed decisions about the choices they have to make. It has guided you through each stage of the search process, highlighting relevant resources for this particular topic area, and describing techniques for searching those resources effectively. Once the relevant research has been identified, this chapter provides information on how to manage the references, obtain full text publications, and assess the quality of the research methodology. Although the purpose of the chapter is to facilitate independent information retrieval, you are encouraged to find a librarian or information specialist, where possible, for expert professional assistance or advice.

### 6.2.14 Key messages

- **If available, contact a librarian who has the skills and understands the context.**
- **Recognize the scenario and formulate a focused question.**
- **Identify the key search terms and compile a list of synonyms.**
- **Decide on the most appropriate study types to answer the question.**
- **Choose the most relevant information sources and apply the search terms.**
- **Start with a broad (or sensitive) search, narrow down by adding additional concepts.**
- **Keep a record of the search strategies and results so that they can be revisited, and revised, later.**
- **Use reference management software to manage the references you find.**
- **Use critical appraisal skills to check whether the information you have found is reliable and relevant.**

### 6.2.15 Further reading

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Danish guides to research methodology:
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# 6.3

# How to write a successful grant application for a research study

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## 6.3.1 Learning objectives

To understand the general components of a grant proposal, by outlining some key principles and tips for success, including:

1. Components typically required in a grant proposal.
2. Process by which granting decisions are made.
3. Tips to increase the chances of success and avoid common mistakes.

## 6.3.2 Introduction

A grant is a monetary award given from a funding body; a grant application contains the details of a proposed project, and is used by the funding body to decide whether to award a grant. Grants are an important financial resource to support research, to enable training and to facilitate sharing of the latest evidence from research.

This chapter provides an overview of the steps for preparing and designing a grant application suitable for submission to a funding agency, with particular emphasis on research projects relevant to health emergency and disaster risk management (Health EDRM). The chapter discusses the components of a grant proposal, how to choose the most appropriate funding body to apply to, how the grant application will be processed and tips to increase the chances of success.

Before applying for a grant, some of the first steps to take are to:

- Recognize a service need or research gap, or have an idea.
- Identify the outcomes that the research study might have and work backwards to design a plan for how to achieve these.
- Generate several ideas and narrow these down, based on what is appropriate and feasible.
- Look for funding opportunities to identify grants that would be suitable for the project and for which the project would be eligible.

- Secure partners to establish a working team, which might include members of the public from the populations that will participate in the research.
- Prepare the grant proposal, and address the items as listed.

There are many guides to help new researchers to prepare a grant application, some of which are signposted in the Further Reading section at the end of this chapter.

### 6.3.3 Grant Proposal

A grant application usually includes a research proposal, which summarizes how the proposed project will be planned, implemented, monitored and reported. The exact content of the proposal will vary depending on the type of grant and the funder's requirements. For example, a grant application might seek funding for academic research on a health emergency or a scholarship to support postgraduate learning, or might be smaller in nature – in order to support attendance at a training event or conference, for example. Sometimes, funds might be sought as seed money for a pilot study or as matching funds to be combined with other sources of funding. Although there is wide variation in proposal formats, Table 6.3.1 shows the components commonly found in grant applications for research studies.

**Table 6.3.1 Common components of grant proposals for research**

| Item | Content |
|---|---|
| **Title** | Short project title. |
| **Summary** | Summary of the proposed study (usually 200 to 400 words). |
| **Introduction and Background** | Background and rationale for the study to show its importance.<br>Description of the current problem and the new study's research questions.<br>Review of existing body of knowledge.<br>Details of the intended participants. |
| **Methods** | Justification for the choice of methods.<br>Description of the methods, including:<br>- study design;<br>- sample size and sampling method;<br>- implementation procedures (for recruitment and follow-up for example);<br>- plan for data collection, analysis and interpretation. |
| **Discussion** | Plan for reporting and dissemination of findings.<br>Expected outcomes and impact of the study. |
| **Limitations** | Limitations of the methods, and risks to the project.<br>Mitigation plans to overcome any difficulties. |

| Item | Content |
|---|---|
| **Timeline** | Time needed for each part of the project (perhaps as a Gantt chart). |
| **Budget** | Budget and justification for separate items.<br>Details of any other funding for the study. |
| **Ethics consideration** | Ethical issues and process for obtaining ethics approval. |
| **Research team** | Information about each member of the research team. |

A key aim for a grant proposal should be to present an exciting idea for a research study, that has been transformed into achievable actions and that will provide evidence to fill an important gap in knowledge. The gap can relate to uncertainties in the topic area (for example, to measure a health problem in an emergency and its impact on the population, or to identify the effects of an intervention) or knowledge mobilization (for example, moving available knowledge from research into practice). The existence and importance of the gap might be supported, for example, by a systematic or scoping review of existing research (Chapters 2.6 and 3.6), statements from experts in the field, data from previous research, examples of similar research, a prioritization exercise (Chapter 2.7), or community-based research and asset mapping (Chapter 3.1). In the proposal, it is necessary to demonstrate the applicants' knowledge of current developments in the field and the ability of the research team to deliver the study and uphold the standard of good quality scientific evidence.

Application requirements vary considerably across funding agencies. For example, some funding bodies encourage collaboration between different organizations, others prefer a simple but clear plan without the complications of project dependencies. For research studies with multiple partners and locations, the grant proposal will require clear identification of the qualifications, experience and roles of each research team member. It will also need a justification for their involvement and the costs of doing so.

### 6.3.4 Grant writing

Grant proposals should be written in a way that will allow peer reviewers from unrelated disciplines to understand the problem to be researched, the methods to be used and the importance of the project. Some of the people that the funder will ask to assess the application may be non-experts, so it is important for the proposal to be understandable to a range of audiences and to avoid jargon. It is helpful to use short and clear examples of what is being studied and why, to provide the assessors with a visual picture of the overall plan.

It is common for funders to ask for a cover letter to accompany the grant proposal and this is an additional way to stress the importance of the study. It is an opportunity to state the need for the project clearly and explicitly, and to show how the proposal meets the eligibility criteria for the grant. The request should clearly state and quantify on what and how the grant will be used, and the benefits to both the researcher and the funder of it being awarded. It is best to use the active voice to emphasize the plan of action. In addition, if there is sufficient space and it is acceptable to include diagrams and infographics, these can be used to illustrate complex concepts. As with the final report of the study (Chapter 6.7), it is important to check the application carefully for spelling and grammar before it is submitted, and it may be useful to employ an editor or ask a friend to proofread it.

**Case study 6.3.1**
**Example of a research grant on Health EDRM** *(1)*

*Project title*: Optimizing a community-based model for case identification, monitoring, and prevention of hypertension and diabetes among Syrian refugees in the Hashemite Kingdom of Jordan

*Funder*: Elrha's Research for Health in Humanitarian Crises (R2HC) Programme. R2HC is funded by the United Kingdom's Department for International Development (DFID), Wellcome, and the United Kingdom's National Institute for Health Research (NIHR).

| Funder requirements | Project characteristics that match the requirement |
|---|---|
| **Scope:** research that will strengthen evidence-based practice around a public health intervention in humanitarian crises. | Research to investigate and improve a community health worker based model for noncommunicable disease care in a humanitarian emergency among Syrian refugees in Jordan. |
| **Impact:** demonstrate the potential scale and impact of the proposed research. | The outcomes of this project will be replicable in other contexts (for example, non-refugee emergencies) and will provide a strong case for addressing continuity of care for urban refugees through community health workers. |
| **Methodology:** robust innovative methodologies of a standard publishable in peer-reviewed academic journals. | Qualitative and quantitative methods (population-based survey) will be used, including a cost-efficiency analysis. Citing previous work of the research team in the topic area will highlight their experience with the chosen methods. |
| **Partnerships:** applicants must have a research team including both a research institution and an operational humanitarian organization | University of Southern California, International Rescue Committee, Jordanian University of Science and Technology, and Brigham and Women's Hospital. |
| **Duration:** 36 months. | September 2018 to August 2021. |

## 6.3.5 Funder requirements and suitability

The funder for a research study might be a (federal or state) government agency, a public or private foundation, or a corporation. The funder will have requirements as to the applicant's legal authority to apply for a grant, whether the applicant is an organization or individual. For example, there are grants specifically aimed at funding partnerships between voluntary and governmental organizations, and grants targeted at people holding an academic position or belonging to certain resident groups. It may be helpful to look at previous grants made by the funder to explore the type of research that they are likely to fund and the content of successful applications.

Grant opportunities might be identified by searching online sources, through the research offices of academic institutions, or by identifying potential funding agencies. Other resources include checking the grant histories of individuals who have similar research interests or asking colleagues with a similar level of expertise. Subscription-based websites, such as Foundation Directory Online and GrantWatch have extensive information in their donor databases.

The National Institutes of Health in the USA, Canadian Institutes of Health Research and the United Kingdom's Wellcome Trust are the top three funding agencies, with the highest number of grants among 12 major funders for health research *(2)*. However, a limitation of all three is that they mainly support academic research at universities in their own countries *(2)*.

The largest source of research and development funding for health is from the business sector, followed by the public sector, and then other sources (including private NGOs) *(3)*. The private sector can be a good source for funding and, although many of these grants support clinical trials on diseases such as cancer, it is worth exploring any that would be a good fit for a project in Health EDRM. Table 6.3.2 lists some websites that contain information for private foundations and corporations that award grants for health research.

**Table 6.3.2. Websites for identifying research funders**

| Funder or organization | Website |
|---|---|
| Foundation Directory Online | fconline.foundationcenter.org |
| GrantWatch "Disaster Relief Grants" | www.grantwatch.com/cat/48/disaster-relief-grants.html |
| WHO Centre for Health Development | extranet.who.int/kobe_centre/en/calls-tors |

## 6.3.6 Allocation of grant funding in different phases of the disaster cycle

There are four phases of the disaster cycle: prevention, preparedness, response and recovery. Research has shown that investing in disaster risk reduction (DRR) measures before a disaster is several times more cost effective than funding the response to disaster *(4–5)*; however, prevention and preparedness are a low priority for attracting funding in comparison to the response and recovery phases. Donors are quick and generous in giving immediately after a major disaster, but donations trail off within a short period. Therefore, finding a way to place prevention and preparedness within response and recovery may increase the chances of success for a grant proposal, as well as providing the stability required for widespread implementation in Health EDRM.

International aid for disasters from 1991 to 2010 was spent mainly on emergency response (US $69.9 billion, 65.5%) or reconstruction and rehabilitation (US $23.3 billion, 21.8%). A smaller proportion of the funding went to DRR (US $13.5 billion, 12.7%) *(6)*. In 2016, foundations and public charities allocated their global disaster-related funding as follows: 42% for response and relief efforts, 17% for reconstruction and recovery, 8% for resilience and 5% for disaster preparedness *(7)*. Furthermore, more than two thirds of private giving stops within two months of a sudden disaster, and all giving peaks by five or six months *(8)*.

### 6.3.7 Developing a grant budget

A vital part of planning the research study that is also vital for the grant application is identifying, well ahead of time, where to get assistance and who is needed beyond the immediate team. This will have an impact on the project's budget; an advisor or programme officer may help to determine what expenses will be regarded as reasonable. For example, funders are unlikely to pay for new computers for all members of the research team or for holding research meetings in expensive locations. What is important is that the funding will be sufficient to complete the research, which means that it is critical to request the correct amount of funding.

An effective proposal budget is an accurate assessment of all expenses, provides justification for each item of spending and explains how the costs were arrived at. The timeline for the project needs to be taken into account, as well as the items for which funding will be requested. It is also important to consider the length of time that might be needed by the host organization for the grant in order to approve the proposed budget (if necessary), as well as how to respond if the costs are challenged.

Typically, a research study's budget will include direct costs and indirect costs. Direct costs are project personnel salaries and employee benefits, equipment, supplies, services and travel. Indirect costs are those incurred in the project which cannot be identified specifically, and usually include the money needed for the services provided by the host organization (for example, administrative, procurement, accounting and finance, security, library and so on). These costs are often referred to as overheads, overhead costs, or facilities and administrative costs. They are sometimes calculated as a predetermined proportion of the project's direct costs.

Expenses for personnel will include some or all of the salary or wage for each person on the project (depending on what proportion of their time they will devote to it), as well as employee benefits such as pension expenses, social security contributions, statutory and voluntary medical insurance contributions.

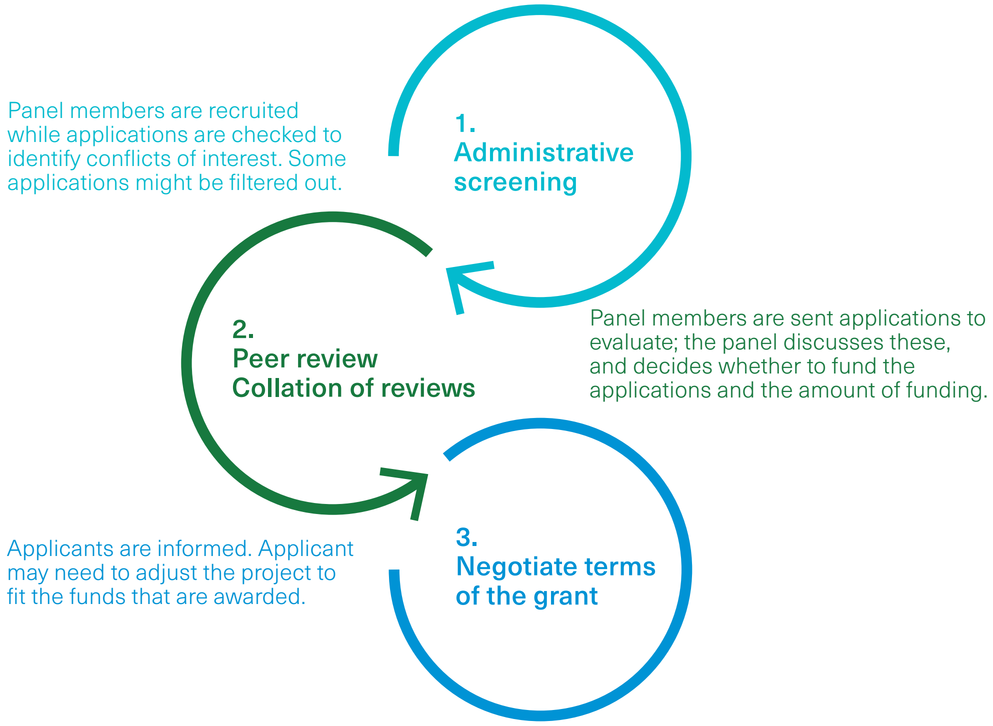
### 6.3.8 Grant review process

Funders wish to choose well-organized and compelling ideas from among the many proposals submitted to them. They will select applicants who they feel are capable of successfully implementing the proposed project, in accordance with the requirements and eligibility criteria for their funds.

The funder's guidelines for the application are usually accompanied by information on the objectives of their grants and criteria for evaluation. To increase the chances of success, it is important that the applicant strictly follows the proper format for the application and submits all the required materials.

After a grant application is received, the funder's administrative staff will usually check its completeness and eligibility for the grant before assigning it to peer reviewers, a specific panel or both. Most decisions on research funding are made by a panel of experts who assess the applications and might interview the applicants. The panel assesses the proposal against a set of criteria. A summary of the assessment and any peer review is usually sent to the applicants, sometimes with an opportunity for them to respond before the funding decision is made. The funder would then either offer the grant to the applicant, decline to do so or, occasionally, offer a smaller amount of funding than that requested. Negotiation with the funder may then be possible, as well as adjustments to the project goals, objectives and timelines to match the reduced funding. The whole process from submission of an application to the decision usually takes at least three to six months and can sometimes take more than a year (Figure 6.3.1).

**Figure 6.3.1 Grant review process**



Panel members are recruited while applications are checked to identify conflicts of interest. Some applications might be filtered out.

Panel members are sent applications to evaluate; the panel discusses these, and decides whether to fund the applications and the amount of funding.

Applicants are informed. Applicant may need to adjust the project to fit the funds that are awarded.

### 6.3.9 Managing a grant

Obtaining a funded grant is an achievement and indicates the proposal's appeal to the funder. Implementing a new grant requires good project management and administration. If the grant is for an organization, the relevant department would set up a grant budget account and oversee logistics of monitoring expenditures. Collaboration may also be needed with the human resources department to hire new personnel. A key next step after the grant is awarded may be an application for ethics approval (Chapter 6.4) and it is important to do this as early as possible, because the process can take several months and the study will not be able to start without the necessary level of approval.

### 6.3.10 Conclusions

There are many resources available that provide advice on preparing grant applications – this chapter outlines how to get started. To be successful, a grant proposal must be persuasive, realistic and written in a way that will appeal to the funder. In the end, success is likely to be a mixture of skill and luck; and the following tips may help:

- Address the objectives of the grant first, and explain how the objectives of the project will complement the grant.
- Identify service and knowledge gaps, and explain how the research will fill this gap.
- Show preliminary data related to the funding call, including records from previous work, feasibility research or pilot projects to demonstrate the proficiency of the research team.
- Show the track record of the research team, including listing related work and bring necessary expertise into the team where this is lacking.
- Choose and be prepared to train responsive collaborators who will complement the initial team and who will help to complete the project, problem-solve, be flexible and maintain a positive transparent outlook.
- Quantify the potential impact of the research.
- Be clear and easy to understand, illustrate with figures, infographics and photographs.
- Support the application with scientific evidence and relevant references.

## 6.3.11 Key messages

- **A grant proposal summarizes the idea and components of a research study.**
- **Connections with reliable people with similar research interests and exploration of funding sources in the applicant's area of expertise will help to ensure that there is a good fit between the application and the funder.**
- **The eligibility criteria for grants and the requirements of funders vary widely, making it important to check grant criteria carefully.**
- **Previous grants made by the funder may provide a good guide to the type of research they are likely to fund and the content of successful applications.**

## 6.3.12 Further reading

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# 6.4

# Getting ethical approval for your research

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## 6.4.1 Learning objectives

To understand the following in relation to applying for ethical approval for a research study in health emergency disaster risk management (Health EDRM), with a focus on WHO guidance:

1. The general processes involved in ethical approval of research projects.
2. The types of document that are usually needed for an ethics application.

## 6.4.2 Introduction

Research is an essential component in public health – it is the gateway to evidence on the effects of interventions, disease trends, health system structures and processes. In the context of Health EDRM, research is especially important for investigating the effectiveness of emergency prevention, preparedness, response and recovery, and providing an evidence base for decision making. Research that involves human subjects, regardless of the form of sample/record taken and study design, require ethics approval in order to ensure that the people who participate in research are treated ethically, not taken advantage of, and that the research procedure is carried out to high ethical standards; this is discussed in depth in Chapter 3.4, with particular issues for at-risk groups described in Chapter 2.5. Researchers have a duty to promote and ensure respect for all human subjects and protect their health and rights *(1)*. Specific morals that need to be upheld include respect for persons, non-maleficence, beneficence, justice and utility. According to WHO *(2),* all research involving human beings should be reviewed by an ethics committee. Studies that involve human participants but are potentially exempt for ethics approval, e.g. using public available data only, should also be reviewed by ethic committees to confirm exemption. Ethics approval should be obtained before the study begins from a recognized ethics committee – this chapter introduces the procedure and basic components required for obtaining ethics approval.

### 6.4.3 Where to request and obtain ethics approval

A research ethics committee (REC) has the responsibility to ensure the ethical safety and scientific merit of the research. It has the authority to reject, approve or cease the research and to require modification to the research protocol. The main responsibility of the REC is to protect the safety of potential research subjects and to evaluate the risks and benefits brought to subjects and the community. In general, RECs evaluate research proposals with reference to established ethical documents *(3-4)*. Each REC may have its own standard. For example, the WHO ethics committee *(5)* is guided by the World Medical Association Declaration of Helsinki *(1)* and the International Ethical Guidelines for Biomedical Research Involving Human Subjects *(6)* . Hence, researchers should check with the REC they intend to approach (in their academic institution, region or country, for example) to identify the documents that will need to be submitted with their application.

RECs are usually based in regional or national public facilities or individual academic institutions. They usually consist of scientific members (with related research expertise) and non-scientific members (with diverse backgrounds) in order to provide for a comprehensive and quality ethical evaluation.

Individual institutions may have their own committees as an internal regulatory process, such as an institutional review board (IRB) or University Human Research Ethics Committee (UHREC). These have the advantage of being able to evaluate the research protocol with local and familiar perspectives and to monitor the study more closely. For example, the community ethics committee of the Center for Bioethics of the Harvard Medical School *(7)* has members from the Greater Boston area, which makes the ethics review a better fit with the local culture and needs. However, financial interests within the studies may present challenges for a local REC such as this to refuse an application or to request significant changes to the research protocol. For that reason, regional or national committees might provide a stronger legitimacy and consistency when reviewing research conducted by the public and research community. For example, the National Health Service (NHS) in the United Kingdom has a Health Research Authority, which is responsible for the management and conduct of national-level research, including the REC process *(8)*.

### 6.4.4 Research approval for studies that will take place beyond local regions

For studies that will be conducted outside the researchers' local region, the researchers should ensure that the proposed procedure is locally acceptable. The study design should take local culture and tradition into account, and there should ideally be input from local researchers *(9)*. Furthermore, researchers may be required to obtain approval from the relevant foreign authorities, as well as from their host institution. This may require a request to a REC close to the target community, to ensure the evaluation of the research procedures for cultural and legal appropriateness. As Wright, Parker and the Nuffield Council on Bioethics Working Group *(9)* argue, the decision-making of funders, research institutions, RECs and many others should be centred on the priorities and needs of the local community they try to support.

When applying to the researcher's host institution, the application should indicate that the study will be an international study and that approval from a local REC will be obtained after approval by the host institution. Likewise, the application to a foreign institution should indicate that approval has been obtained from the host institution. When preparing these applications, it is important to remember that the different RECs may follow different processes and require different documents.

### 6.4.5 What if no REC is available in the affected area?

If no REC is available in the affected region/country during a health emergency or disaster, alternative actions may be needed to obtain ethics approval *(10-11)*. There is no consensus guideline for this type of situation, but some possible courses of action and their limitations are shown in Table 6.4.1.

**Table 6.4.1 Obtaining ethics approval if a local REC is not available: Some possible actions and their limitations**

| Action | Limitation |
|---|---|
| Ask the relevant local representatives or authorities (such as village elder or community leader) for agreement and obtain ethics approval from researchers' local region. | Approval might be biased to one or a small number of local authorities. |
| Ask the relevant local representatives or authorities (for example, village elder or hospital director) to organize a review committee. | It takes time to organize a committee and the members might not have the necessary experience for review and decision. |
| Obtain ethics approval from an international organization (such as WHO). | Approval might not have considered local context. |
| Obtain approval from an established special review board. | It takes time to organize the committee and must be organized by a trusted organization. |

### 6.4.6 Types of ethics review

Different levels of ethical review may be required depending on the invasiveness of the procedure, urgency and the design of the research. Furthermore, review levels vary across different institutions. The researcher should check the requirements of the target institutions before submitting an application. WHO uses five common types of ethics review for proposals *(5)*, which are outlined below.

**Full committee review of proposals**
Research proposals that present more than minimal risk to human subjects are reviewed by two REC members who present the proposal to the full committee, which then has a general discussion before reaching a consensus decision (see Section 6.4.7). Researchers responsible for the proposal under review are subsequently invited to respond to queries

raised and to provide clarifications or justifications.

**Expedited review of proposals**
The proposal is circulated for expedited review when the research procedures present no more than a risk of minimal harm to the research participants or communities. In this case, the proposal is sent to two REC members who are required to provide their feedback to the secretariat within 15 working days. The proposal is then either approved or returned to the researcher for further action.

**Exemption from REC review**
Proposals are exempted from review if they represent less than minimum risks to participants.

**Accelerated review**
In a public health emergency, such as the investigation of a disease outbreak or a disaster relief operation, an application may be submitted for accelerated review. This is discussed further below.

**Continuing review**
Since ethics approvals are valid for a limited time period, the REC reviews the progress of the study at periodic intervals. In order to renew the approval, the researchers should submit the necessary documentation to the REC before their approval expires.

### 6.4.7 Definition of minimal risk

In some decisions around ethics approval, the REC may consider the concept of "minimal risk". There is no global consensus on minimal risk, but similar definitions are used by many organizations and countries. For instance, Australia, Canada, South Africa, the USA, and the Council for International Organizations (CIOMS) have a standard for minimal risk which revolves around comparisons and interpretations of 'everyday risks', 'routine examinations' and 'best interest' of the studied population. These standards need to be adjusted for vulnerable research participants such as prisoners, incapacitated adults and children *(12)*. Researchers should check the minimal risk definition of the REC they are applying to before submitting their application for ethics approval.

### 6.4.8 The need for accelerated review: Limitations of the non-emergency ethics review process during emergencies

Although most of the ethical issues in emergency-related research are not unique to emergencies, in an emergency the perceptions of potential harm, benefit, and trust (including the patient-provider relationship) differ, and this should be considered in the ethics review, as discussed in Chapter 3.4 *(13)*. Furthermore, research during an ongoing emergency or disaster is likely to require a faster approval decision. Accelerated reviews are designated for this purpose, but some existing ethics review system cannot accommodate these. In considering this, Kayano and colleagues *(14)* emphasized the importance of ethics review systems evolving constantly; this is discussed in Case Study 6.4.1.

**Case Study 6.4.1**
**The value of an accelerated ethics review process**

Many existing ethics review systems are established to operate in non-emergency situations. However, for emergency research, the complexity of the emergency setting may make it difficult to address practical ethical issues. In such contexts, ethics governance may need to consider non-ideal ethical and methodological approaches rather than insisting on the ideal situation in humanitarian research *(15)*. Decision making will require striking a balance between speed and ethics, with the addition of the voice of the affected communities.

For example, during the Ebola outbreak in 2014-2016, WHO *(16)* was responsible for reviewing and discussing ethics for various interventional and observational studies to control the outbreak. The WHO REC established a subcommittee to conduct accelerated reviews to facilitate this process. This was the first time that the accelerated review was put into practice. The subcommittee reviewed 24 new and 22 amended applications, with an average reviewing time of 6 working days.

### 6.4.9 The research protocol: what to include when preparing an ethics application

This section lists the documents commonly required as part of an ethics application. However, researchers should always check and understand the specific requirements of the REC they are applying to before submitting their application.

**Research Protocol**
This is the core document of the application. It describes why the study is needed and how it will be conducted. The WHO recommended format for a research protocol is that it should have the following components *(17):*

- **Project summary:** This summary should include the rationale, objectives, methods, participants, time frame and expected outcomes.
- **General information:** This should include the protocol title (identifying number and date), investigators, sponsors and the locations and institutions where the research will be done.
- **Rationale and background information:** This should describe current knowledge about the research topic and intervention, and the need for the research to be conducted in a disaster, rather than a non-disaster, setting. The proposal should provide basic information about the target population, and the potential benefits and harms of the intervention to them. It should also explain the expected benefits from the research and how these outweigh any potential harms of the study.
- **Study goal and objective:** This should include the intended outcomes and aims for the research, and should be considered alongside the research question (Chapter 3.5).
- **Study design:** This should include the type of study (as discussed in Section 4 of this book) *(18)*, target population, the recruitment procedure, research or diagnostic tools and duration of the study. Information on the study's inclusion and exclusion criteria and any criteria for withdrawal should also be mentioned.

- **Methodology:** This should provide detailed information about the research procedure. This would include information on how the following will be conducted: interventions, measurements, observations, laboratory investigations, and procedures. How participant confidentiality will be ensured should also be included. Standardized and clearly defined procedures will be required for any sites where special protocols are needed. For studies in disaster settings, providing participants with sufficient information about the study and the freedom for participants to choose whether or not to participate are especially important (see Chapter 3.4) and should be clearly stated in the protocol. If the study involves an intervention, the standardized and documented procedure (for example, the frequency of study visit, intervention procedure) should be clearly described and evidence supporting the interventions should be provided (see Chapter 3.3). The procedure for receiving questions and feedback from participants should be clearly defined. If the study is a randomized trial, additional information on randomization, blinding or masking and any stopping criteria for ending the research prematurely will be needed (Chapter 4.1).
- **Safety consideration:** This should describe how safety of participants will be ensured and how adverse events will be recorded, reported and managed.
- **Follow-up:** This should describe what follow-up activities will be provided to the research participants and the duration of this follow-up – for example, follow-up activities relating to data collection or monitoring of adverse events.
- **Data-management and statistical analysis:** This should describe how the data collected will be processed, stored and analysed. Physical and electronic data may have different management protocols and information should be provided about which personnel will have access to the data, and how the confidentiality of participants will be protected.
- **Quality assurance:** This should describe the quality control and quality assurance system for the research, e.g. clincal monitors and data management.
- **Expected outcome of the study:** This should discuss how the study results might contribute to the advancement of knowledge, how the findings will be made available, and how it may impact on the health services, systems and policies.
- **Dissemination of results and publication policy:** The dissemination process for the findings of a study should include information on the method, policy and responsible personnel, target audience (relevant policy makers, scientific media, the community and participants, for example).
- **Duration:** A detailed timeline of the project should be provided, ideally in months and beginning from the point that ethics approval is received.
- **Anticipated challenges:** This should include the foreseeable problems and possible solutions for the study.

- **Project management:** This should describe the roles and responsibilities of each member of the research team.
- **Ethics:** This should describe the ethical consideration. Even in the context of emergency and disaster situations, ethics issues such as time to reflect on to take part in the study or not and the right to withdraw, should be respected. Any procedures that might raise specific ethical issues should be discussed. This section should also describe how informed consent will be taken during recruitment and the relevant documents should probably be included in the application, as discussed below.
- **Conflict of interest:** The researchers should declare any interests that any of them have which are related to the study or its results and might be regarded as a conflict. WHO provides guidance for this online in Guidelines for Declaration of Interests *(19)*.
- **Budget and other financial support:** Some RECs require details on the study's budget and funding source. Researchers should check whether the REC they are applying to requires this.
- **References:** A list of the cited references should be provided to support the content of the protocol.

**Informed consent form**
An informed consent form is a document used for recruiting potential participants to the research study and obtaining their agreement before they enter it, receive the intervention or have data collected. The form should show study information, and the contact details of the responsible investigators, the ethic committee and of the research institution. It also needs to have space for the name and signature of the researcher (or their representative), the participant and, if necessary, a witness. The procedure of obtaining the informed consent should also comply with international guideline, like the International Ethical Guidelines for Health-related Research Involving Humans (b), while making the informed consent form.

*(b) Council for International Organizations of Medical Sciences. International Ethical Guidelines for Health-related Research Involving Humans. Geneva. Switzerland: CIOMS. 2016 https://cioms.ch/wp-content/uploads/2017/01/WEB-CIOMS-EthicalGuidelines.pdf (accessed 13 Feb 2021).*

Procedures should be in place for non-written consent if, for example, potential participants are visually impaired or illiterate *(1)*; obtaining their consent is likely to require the presence of an independent witness and a note (written, audio or video) indicating the person's willingness to join the study.

**Patient information leaflet (if available)**
The patient information leaflet is a document providing more detailed information on the study, which would be given to potential participants and those who are recruited to the study.

**Any associated study instruments**
These include questionnaires, interview guides, focus group discussion guides or other documents related to the research intervention. They may be required to be in English and the native language of the participants. The collection procedure should give an explanation and reason for the data collected, especially if any of this is sensitive data.

**Final approval document by the other scientific/technical review committee, or peer reviewers**
If the research intervention involves novel technology or instrument, its implementation should have been already reviewed and approved by other relevant peer reviewers or the scientific/technical review committee. The approval document should be provided with the application.

**Principal investigator's response to previous review (if the protocol has been submitted before)**
If a resubmission is being made to the REC, perhaps following "conditional approval" (which is described below), the researcher should indicate any changes made in the revised protocol in response to the previous review.

**Comments made by the other scientific peer review groups (if the protocol has been reviewed by another REC or other committee)**
In international studies, approvals from multiple REC may be required. In such cases, any other submissions or approvals should be mentioned, including proof of these.

**Information and curriculum vitae (CV) of the researcher(s)**
Information, including a curriculum vitae (CV) for each member of the research team may be required by the REC and researchers committee should check the requirements for this with the REC that they will apply to.

**Data collection forms, case report forms, patient diaries, and so on (if the study will use these)**
Some RECs require these data collection documents to be submitted. The format of each will depend on how the research has been designed, and how the data will be collected and stored.

**Recruitment material (if available)**
Recruitment material refers to, for example, any advertising tools that will be used to recruit participants to the study. These might be pamphlets, posters or other media. The materials should be compliant with the local culture and language, and should contain sufficient contact information for the researcher and their organization.

### 6.4.10 Providing potential participants with information on the study

As noted above, the patient information leaflet and informed consent form provide essential background information on the study to potential participants, in lay language. Several components are recommended for both documents. Firstly, they should provide the background and reasons for the study in the target community and explain why the person is being invited to participate. Secondly, they should describe the selection criteria. Thirdly, there should be a clear explanation of the research procedure (including number of visits and estimated research duration), potential safety concerns, rights of participants, data confidentiality, where and how participants can ask questions or raise concerns, procedures and reason for the collection of any sensitive data and the right of the participant to withdraw from the study. Fourthly, contact information of the responsible researcher, the REC and detail of the research institution should be provided.

These documents should include both English and native language versions. In some cases, the native language version might be prepared after ethics approval *(17)* but the REC should usually be provided with the translated document. This is particularly important in international studies that involved populations that speak different languages. Furthermore, if the study will involve multiple distinctive groups, tailored consent might be needed for each of them.

## 6.4.11 Approval status

After reviewing an application, the REC will usually make a decision that the application is approved, needs modification or is rejected. RECs usually use four classifications to indicate the status of an application after they have processed it (Table 6.4.2).

**Table 6.4.2. The description of each different approval responses of ethics application**

| Status | Description |
|---|---|
| **Approved as submitted** | The proposal is approved and no modifications are required. |
| **Approved conditionally; requires amendments or clarifications** | The REC requires clarification or amendment about the application, which the researcher is required to provide before it can move forward. The proposal would be re-evaluated after re-submission. |
| **Not approved; requires additional information or rewriting** | The REC considered that the proposal was not acceptable but is willing to consider a revision of the protocol if this is submitted in a new application. |
| **Rejected** | The REC considered that the proposal was not acceptable and did not advise re-submission. |

## 6.4.12 Responses to questions from the REC

After the research protocol has been submitted, the REC may have comments or questions for the researcher about it. Researchers are typically required to respond to these queries and the requested amendments by preparing a note which includes a point-by-point response to all queries and to submit a revised protocol which shows the changes they have made.

## 6.4.13 Other communications with the REC

This section describes a variety of situations which need to be reported to the REC, according to WHO *(20)*.

**Progress report**
For non-cross-sectional studies, a progress report might be required by the REC on an annual basis. This would cover the status of the study, number of participants (recruited, withdrawn and completed), a summary of any major changes to study procedures, serious adverse events,

participants' complaints, and significant updated information or deviation from approved activities which are related to safety or participation.

**Application for continuing review (if needed)**
If a study needs continuing review, the researchers may need to submit a renewal application including information justifying the renewal and a progress report of the ongoing study, a report from their study's Data and Safety Monitoring Board (if available), and any amended or new documents. Researcher should ensure approval is obtained before the existing approval is expired.

**Application for Amendment**
If the originally submitted documents and study protocol are amended after approval, the researchers should notify the REC about these amendments. Revised documents include an explanation of the amendment and an amended protocol (highlighting the changes) should be submitted. If the amendment involves significant changes in the study design, additional justification should be provided. The amended protocol should not be implemented before it is approved.

**Project closure**
When the study is successfully completed or terminates early, the researchers should inform the REC and provide a completed set of documents. This should include the final report with a summary of the study's findings, the latest progress report and any Data and Safety Monitoring Board reports (where applicable), and any other documents required by the REC.

**Protocol Deviation**
For any protocol deviation has been made during the research (changes of the protocol without the agreement by the sponsor and prior review and documented approval/favourable opinion from the IRB/REC of an appropriate amendment) (ref. a), it should be promptly reported to the REC.

*(a). Integrated Addendum to ICH E6 (R1): Guideline for Good Clinical Practice E6 (R2). Swiss. ICH. 2016. https://www.ich.org/fileadmin/Public_Web.../E6/E6_R2__Step_4_2016_1109.pdf*

**Adverse events**
According to *Safety of Medicines: A guide to detecting and reporting adverse drug reactions* published by WHO, an adverse event is any untoward medical occurrence that presents during treatment with medicine, but which does not necessarily have a causal relationship with the treatment *(21)*. In addition to these, some REC also include non-medical occurrences as adverse events. Researchers should check the specific requirements of their REC and ensure that adverse events are reported according to these requirements.

**Serious adverse events**
A serious adverse event is defined as an untoward medical occurrence which is fatal, life-threatening, requires inpatient hospitalization, results in persisting and significant disability to the subject or causes congenital anomalies or birth defects *(21)*. These should be reported as per REC required. As with adverse events more generally, some REC also include serious nonmedical occurrences as serious adverse events and researchers should check the specific requirements of their REC to ensure that they report serious adverse events appropriately.

## 6.4.14 Conclusions

Research ethics applications and approvals are necessary before research involving human subjects, except for those studies that will be limited to publicly available, anonymous data. This chapter provides a general overview of different types of ethics review, procedures, documents required and other important points, which are part of the WHO guidelines for ethics approval. However, the variety of national and institutional policies around ethical approval mean that there is no single, globally-agreed standard or requirement that applies to all research ethics systems or RECs *(14)*. Researchers should therefore always check the specific requirements of the REC they are applying to before submitting their application.

## 6.4.15 Key messages

- **All research studies involving human participants should be reviewed and approved by research ethics committee. It is the committee's decision whether a study should be exempted from the full reviewed process.**
- **Research should be conducted in ways that protect the safety and confidentiality of the participants, both physically and mentally (in protocol and document) and be carried out in accordance with the principles underpinning the Declaration of Helsinki.**
- **The type of ethics review required will depend on the nature and the urgency of the study.**
- **Current ethics review procedures might not be fully applicable to the challenges encountered in the Health EDRM context, especially during rapid onset emergencies and disasters because of the relatively long lead time of non-emergency ethics review processes. Changes in the ethics review procedure are needed to accommodate the special needs for emergency researches.**
- **Ethics application requirements vary across REC. Researchers should check the requirements of the REC they plan to submit their application to.**

## 6.4.16 Further reading

Council for International Organizations of Medical Sciences and WHO. International ethical guidelines for biomedical research involving human subjects. Geneva, Switzerland: CIOMS. 2002 https://cioms.ch/shop/product/international-ethical-guidelines-for-biomedical-research-involving-human-subjects-2 (accessed 10 January 2020).

Integrated Addendum to ICH E6 (R1): Guideline for Good Clinical Practice E6 (R2). Swiss. ICH. 2016. https://www.ich.org/fileadmin/Public_Web.../E6/E6_R2__Step_4_2016_1109.pdf Kayano R, Chan EY, Murray V, Abrahams J, Barber SL. WHO Thematic Platform for Health Emergency and Disaster Risk Management Research Network (TPRN): Report of the Kobe Expert Meeting. International Journal of Environmental Research and Public Health. 2019: 16(7): 1232.

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Policy on research involving human participants. London, United Kingdom: Wellcome Trust https://wellcome.ac.uk/funding/guidance/wellcome-trust-policy-position-research-involving-human-participants (accessed 10 January 2020).

World Medical Association Declaration of Helsinki - Ethical principles for medical research involving human subjects. Ferney-Voltaire, France: World Medical Association. 2013 https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects (accessed 10 January 2020).

## 6.4.17 References

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10. Calain P, Fiore N, Poncin M, Hurst SA. Research ethics and international epidemic response: The case of Ebola and Marburg Hemorrhagic Fevers. Public Health Ethics. 2009: 2(1): 7-29.
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19. Guidelines for declaration of interests (WHO experts). Geneva, Switzerland: WHO. 2017. https://www.who.int/medicines/news/2017/Guidelines_for_Declaration_of_Interests_WHO_Experts_51b2CRD.pdf (accessed 10 January 2020).
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# 6.5

# Doing Health EDRM research in the field

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## 6.5.1 Learning objectives

To understand the following in the context of doing health emergency and disaster risk management (Health EDRM) research in the field:

1. Key preparations necessary before conducting research in the field.
2. Logistics involved in undertaking field research and data collection.
3. Key elements needed for a successful deployment to the field.

## 6.5.2 Introduction

Fieldwork is a critical component of Health EDRM research. As discussed elsewhere in this book, it may be necessary to conduct real-time research during health emergencies and other disasters, to inform the response, build the evidence base and identify lessons for strengthening existing strategies and processes for Health EDRM.

In order to maintain the integrity of the research being conducted, careful planning and risk assessments should be made for all stages of the process. When planning to undertake research in the field, it is important to ensure adequate preparation and make provisions to maintain operational independence so that the research process does not burden your hosts. This needs to recognize that sometimes, a sustained period in the field is needed – for weeks or even months. Personal safety must be considered, including personal protective training, vaccinations, security in the field and cultural competence. Researchers must also be prepared for rapidly changing situations and have resilience to deal with change and uncertainty. This chapter sets out key practical considerations for those planning to undertake research in Health EDRM.

### 6.5.3 Preparation

The preparation phase is critical to ensuring that fieldwork undertaken for Health EDRM research is effective, safe and contextually appropriate. There are several areas of importance that need to be planned carefully (Table 6.6.1). Deficits in any aspect of preparation can delay research, extending the length of studies and time required in the field, as well as potentially posing a risk to data quality.

**Table 6.5.1 Key points to consider in preparing for research in the field**

Ethical and governmental approvals for research and fieldwork

Travel considerations, including letters of invitation and visas

Context analysis

- Locally available resources
- Cultural competence
- Socio-political environment
- Scale of emergency
- Risk assessments

Identification of and communication with local command and control structure

Plans for site visits and pilot scoping studies

Equipment and protocols

- Preparation of physical equipment
- Training on use and handling of equipment, as required
- Well-defined protocols for data gathering
- Protocols for safety of data and equipment

Data and specimen collection (if required)

- Human and physical resources
- Specimen handling and transport

### 6.5.4 Relationship and team building

Leaders should be identified for key aspects of the research. Describing the specific roles and responsibilities of team members early can minimize the potential for confusion as the research progresses. The person leading the research is typically called the principal investigator (PI). The descriptions of the roles and responsibilities for members of the research team should be delegated by the principal investigator. Local relationships and networks are essential to all aspects of fieldwork, including safety and security, data quality and collection, and the ultimate dissemination of results (see Chapter 6.7). Such relationships can often be brokered by partners – for example, in-country agencies, such as UN country offices, government agencies such as the Ministry of Health, or local NGOs. Significant expertise among local experts and stakeholders should be identified early on and these individuals brought into the research team.

Researchers should work together to identify and agree team structure, especially between international and local team members where relevant. In Health EDRM research, the balance of personnel within a research team may vary *(1)*. For example, a field research group may be attached to an emergency medical team, which would require its own permission to assist the research team, or the research team may work independently, which would mean that they require specific permission to work in the field. Research-related fieldwork often comprises multiple trips, and each trip must be planned carefully before departure. It is important to understand the context of the environment that you are visiting, including potential political and social tensions, and assess how the presence of the research team will be perceived within this context.

### 6.5.5 Before you start

A formal mandate for research must be received before initiating fieldwork, usually by way of an invitation from the government and emergency control centre. Given the often sensitive nature of data that are collected in the field, many studies are classified as research by involving governing bodies or universities. This usually makes additional local ethical approval through these institutions a necessity (see Chapter 6.4). Considerations necessary for obtaining ethical or governmental approvals, including the development of proposals, should be prioritized, ideally prior to arrival *(2)*. In emergencies, waivers or expedited reviews are often granted; however, even these processes can take days to weeks. If the need for approvals is not considered in a timely manner, fieldwork can be delayed. Fieldwork benefits from reaching out to networks on the ground and engaging communities at the earliest opportunity to communicate research intentions prior to arrival. Furthermore, it is important to establish protocols for all aspects of the fieldwork (including data gathering and analysis, equipment use and handling, communication and feedback loops and so on) before deployment, and ideally before an emergency even occurs. Although specifics often change upon arrival in the field, having plans in place at the outset that can be adapted as necessary is preferable to minimal pre-arrival planning. Many established response organizations have standard operating procedures; it is imperative that researchers review any such guidelines available from affiliated organizations before they consider establishing new procedures.

Specialized protocols are vital in research for consistent data quality and collection, especially when in a volatile environment. For example, sample collection and testing processes in laboratories are usually well documented with standard operating procedures in place. It is important to know which laboratories can and will carry out the tests, where they are, what their requirements are for submitting samples, and who has the responsibility for keeping the standard operating procedures up to date. All other aspects of the research study should use standard operating procedures reviewed and approved by the principal investigators. All members of the research team should be trained on the standard operating procedures, with written acknowledgement showing training completion. It is essential to have a systematic approach.

### 6.5.6 Logistics and risk assessments

It is important to establish early on the local logistic arrangements, and whether these include collection of staff on arrival, transportation and lodging. You should seek out information describing local availability of resources (internet, power, water, health care). You should research the culture and socio-political environment, along with the scale of the emergency itself, to allow you to consider how best to prepare for these factors, as well as undertaking a robust risk assessment. Risk assessments are an important part of your preparation activities and should include a detailed account of all possible threats and vulnerabilities associated with fieldwork. These should be informed by reliable information such as ministry recommendations, UN situation reports, consultation with local partners and key contacts. When you have identified potential risks, decide on risk mitigation and reduction measures that will be employed before, during and after the fieldwork. This information will help in formulating initial fieldwork proposals and pilot studies, and in planning the logistics of initial site visits.

### 6.5.7 Equipment and supplies

Equipment, including computers with the required software already loaded and data backed up to local drives, should be ready for deployment. Ensure that all electronics are compatible with, or adaptable to, local electrical voltage levels, to prevent short circuiting and potentially irreparable damage. Training in use of equipment and technical facilities is essential to ensure familiarity, confidence, and reliability in the field, and should be conducted routinely so personnel are prepared before emergencies.

Planning and protocols for specimen collection are also important. This may include kits and packaging for specimen (blood, urine, faeces for example) collection and storage (that is, necessary containers and transport media). In nutritional surveys or environmental epidemiology studies, measurement tools may be also needed, such as callipers, scales, or peak flow meters. Where cold chains or other transport mechanisms are required, logistics should be investigated and planned for ahead of arrival. Obtaining proper paperwork for security clearance may also be required when transporting medical equipment or laboratory supplies.

Data security must be an integral part of research designs and proposals. Increasingly, research permission, from the home or host organization is made conditional on the development of a robust risk assessment and risk reduction measures. Data security is essential in all settings where research is performed. Often regulations and guidelines are in place to ensure the same standards of data protection are in place in developing country settings as in high-income settings. Usual data security measures should not be relaxed in emergency contexts, as the release of sensitive information may be more harmful to the community involved (for example, harsher stigma for sexually transmitted diseases such as HIV/AIDS). For electronic data, it is important to prepare physical security of databases and the devices on which they are stored (such as laptops), safe servers and data access protocols, including personnel rights. Where paper-based data are used, it is important to retain procedures similar to electronic data, as well increased physical security, such as the use of a safe.

### 6.5.8 Special considerations for researchers coming from abroad

International research-related fieldwork often comprises multiple deployments, and each must be planned carefully before departure. It is important to understand the context of the environment that you are working in, including cultural norms and potential political and social pressures, and assess how the presence of the research team's international staff will be perceived within this context. It is also essential that each team member is declared medically fit for deployment and safe to travel before planning to undertake research in the field.

Before deployment, researchers must be familiar with security considerations, including any organizational guidance. In addition to relevant security trainings (for example, UN online courses such as BSAFE and SSAFE), basic first aid training can be beneficial, remembering that some settings may be far from medical assistance. Other types of training which may be helpful include deployment training, psychological first aid, managing data, and safeguarding *(3)*. Some organizations also conduct residential simulation exercises where new staff can engage in a deployment.

Finally, you should identify those personal items (Table 6.6.2) and equipment (Table 6.6.3) that you might wish to bring into the field.

**Table 6.5.2 Personal items to consider taking to the field**

| **Personal items to consider will be dependent on the need for domestic or international travel, the environment, climate and destination. Considerations include:** |
|---|
| Travel documents (passport, letters of invitation, visas, insurance card/coverage information, vaccination records), and photocopies/electronic copies (essential if international travel is required). |
| Mobile phone, charger, and local SIM (subscriber identify module) card, external battery packs. |
| Personal computer and charger. |
| Power adapters/converters and extension cords. |
| Headtorch. |
| Money (local currency and US dollars) and secure holder (such as a money belt). |
| Medications (required routine medication and prescriptions as well as additional prescription medications, antimalarials if in malaria endemic setting, back up medications). |
| Well-stocked first aid kit (including, at minimum, plasters, bandages, gloves, tape, cleansing wipes, creams, scissors/tweezers, over-the-counter medications, and distilled water). |
| Toiletries, mosquito nets and repellent, and sunscreen. |
| Clothing and footwear that is appropriate for both local climate and culture. |
| List of emergency contacts (personal and local), with at least one memorized. |

**Table 6.5.3 Equipment and resources likely to be needed for undertaking field research**

| |
|---|
| Computers, tablets and relevant software. |
| Internet connectivity devices (routers, mobile hotspots, and so on). |
| Mobile phones, chargers, and local SIM cards. |
| Camera (including charger and spare storage media). |
| Power adapters/converters and extension cords. |
| Printer/copier. |
| Corded telephones/telefax. |
| Data storage options: USB (universal serial bus) storage device, compact discs, cloud storage, locked safe/filing cabinet. |
| Calculator. |
| Stationary: notebooks, paper, pens/pencils, stapler, hole punch, binders, clip boards and so on. |
| Telephone address list to include reference centres and contacts of authorities and experts. |
| File templates. |
| Standard questionnaires. |
| Consent forms for individual-level data collection, photography and so on. |
| Standard operating procedures, handbooks, relevant articles, and other reference materials. |
| Maps, geographic positioning system (GPS). |
| Laboratory equipment. |
| Sample containers and sample taking equipment. |
| Sample storage equipment (such as coolers and so on). |

## 6.5.9 Safety and security in the field

Safety and security are of paramount importance. These factors should be considered before departure, upon arrival and continually thereafter. Given the complexity of safety efforts, it can be useful to appoint a safety officer. This person can hold responsibility for ensuring the safety of the entire team, conducting frequent assessments and alerting team members of concerns.

When arriving at lodgings, evaluate the safety of the building and premises. While travelling, it is generally recommended to identify protective measures, such as gates, security guards, and doors that lock and close. Keep valuable personal items safe – ideally in a locked cabinet or safe – and have multiple duplicates stored in different locations (bag, under bed, and so on) in case of theft. Consider a room that is on the second floor or above, as higher levels may pose a lower risk of break-ins, and consider bringing with you a door jam or security bar to ensure safety whilst asleep. It is also useful to evaluate resources available on the premises, such as power sources (including a generator) and water.

Travelling and working in pairs is good practice, and should be done whenever possible. Transportation also poses a risk, particularly in areas where road traffic crashes happen frequently. If a vehicle does not appear to be roadworthy or does not have seatbelts, find another option. Although this may cause a delay in getting to or from the field, personal safety is essential. It is best to travel with drivers that are reputable and reliable. If not already established, these individuals or companies can likely be identified through trusted local networks. When travelling by car, it can be safer to keep valuables in the boot (trunk), if it is locked. Always leave an itinerary with someone, so it is known where in the field you are going and when you are expected to return.

A secure field office with complete and robust information technology and communications (satellite telephone, radio communications, and, if possible, field video-conferencing capacity) can be invaluable. You may also need specialized protective equipment and medical supplies. For those travelling from another country, incidents tend to happen towards the beginning or end of trips, when researchers are either completely unfamiliar with the environment or have become familiar enough to let their guard down. Remember that risk assessments to evaluate safety and security should be reviewed frequently and anytime there is significant change in the context or you are involved in an incident/near-miss event. Ensure that you follow your organizational policy for reporting incidents and near-miss events so appropriate actions can be taken. Local organizations can be asked to provide security briefings and insight into day-to-day risks that may not be widely known.

### 6.5.10 Relationship management

Research is a two-way process: researchers and the community involved in research both benefit from the process, but trust is required to manage this relationship *(4)*. This is generally achieved by demonstrating reliability and communicating the value of the research to the community, a process that can take some time. However, if research efforts are rushed before connections are established, people may develop mistrust or false beliefs regarding both the researchers and their work. Importantly, a range of contacts should be established, including community members, academics, medical professionals, and governmental and nongovernmental parties. These groups can help to understand local dynamics: social, cultural, economic and political. They are also key to the data gathering process itself, as input and/or data will likely be required from a range of partners and a variety of groups can help to cross-check information.

### 6.5.11 Implementing research

When implementing research, review ethical approvals and in-country protocols for research, and follow any policies requested in these documents (see Chapters 3.4 and 6.4). Violations of local codes of conduct are not only detrimental to research, but can be illegal, disrespectful of local sensitivities or harmful to participants. If any policies surrounding consent, data collection, or sharing of results are unclear, be sure to check in with a representative of the institutions granting ethical approval.

Consent is typically necessary to collect individual level data. Although language and literacy barriers can sometimes make it challenging, obtaining informed consent is essential; this is discussed in Chapters 3.4 and 6.4.

Coordination and logistics support should be agreed through prior development of operational protocols and agreed standards. This might apply for specialist equipment and software as well as the basic approach to data collection, research and evaluation. Prior training, including formal exercises, in use of equipment and technical facilities is essential to ensure familiarity, confidence, and reliability in the field. It is important to note that, when using technology for data collection in the field such as tablet computers or cameras, consideration should be given to whether it is likely to be acceptable to the community (discrete or obtrusive). When using such technologies, there are also more practical considerations such as internet accessibility, power and charging limitations, and the security of any electronic equipment.

### 6.5.12 Processes and mechanisms for research in the field investigations

The research field investigation team should share responsibility using agreements and protocols, clarifying who will lead before any investigation is undertaken. This will also make it easier to transfer responsibility back to the local team when the research field investigation team leave. Within this approach, it may be helpful to compartmentalize aspects of the investigation, for example, by clarifying issues related to data collection and communication of findings.

The timelines for reporting should be discussed and agreed at the outset. Minutes should be taken and disseminated at all research update meetings, listing the agreed actions and the person responsible for each action. It is important to document all decisions and the rationale used to make them, including what information was available at the time. Developing a clear schedule for the reports and updates that are required makes it possible to arrange key field work and meet all the internal and external demands for reports and summaries in good time. For example, it is often useful to release statements to the media at about midday to fit with their publication schedules in print or visual media. Communication with local media should be carefully coordinated and approved with the local incident controller. The release of incomplete research information, or information presented in a manner that is not contextually appropriate, could cause problems.

### 6.5.13 End of research studies or handover

Research teams are often made up of diverse partners and stakeholders that may take part at varying stages of the research. The pre-implementation and implementation phases are usually seen as an “all hands on deck” collaboration of researchers, while data collection in the field can continue for many months to years under the direct, daily guidance of local team members. Whether data collection is ongoing or the project is in a close out phase, certain procedures can be followed to ensure a smooth transition. Generally, project close out and researchers’ departure from the field should be planned well in advance, and discussed and agreed between the research team supervisor and colleagues.

Factors to consider at the conclusion of fieldwork, include data and equipment transport, sharing of results, and personal wellbeing, including psychological debriefs.

### 6.5.14 Data storage and reporting

Data must be archived in a secure and organized manner, accessible only to those parties that may need to continue reviewing them(see also Chapter 4.4). If some results (laboratory or clinical) are outstanding, there must be a plan in place to ensure that these are communicated to partners in a secure fashion (typically using electronic safeguards).

### 6.5.15 Dissemination

A preliminary report must be prepared prior to departure, so that critical results can be shared in a timely manner, and a researcher should be appointed as lead writer to complete the final report. Local institutions and ethics committees that have supported or approved the fieldwork may require internal review of results prior to wider dissemination. While this may take time, it is often expedited for urgent matters. When appropriate, results should be shared with all stakeholders. This may include non-scientists, such as government parties and the general public. In such cases, it is essential to employ strategic scientific communication strategies using layperson language.

### 6.5.16 Health and wellbeing

Those involved in the data collection and research should be offered a debrief to discuss the challenges and opportunities encountered during their time in the field. This should be used to inform existing policies and processes. Organizations may also wish to consider offering a period of rest and recuperation to support staff health and wellbeing. This is especially relevant where researchers have been working in fragile or high-risk environments for an extended period of time.

Individuals should be offered the opportunity to discuss any health requirements confidentially. This can include any onward referral to mental health and wellbeing services, counselling and/or ongoing medical support as required. It is important to refer to any health monitoring processes that may be in place nationally if researchers have been working on or in proximity to infectious diseases.

### 6.5.17 Conclusions

Undertaking fieldwork is important, but can be challenging, especially in emergency or disaster contexts. It is essential that all research has a local mandate to be carried out. Preparation and good organizational skills are essential. It is important to use pre-prepared plans in a flexible way while working with local stakeholders. Help from local agencies should be sought, especially when working in unfamiliar contexts. Where findings are shared in the scientific literature the work of all team members should be acknowledged and ethical approvals may need to be set up at the start to allow this to happen. Such reports are vital to improve practice in the future. Other forms of research dissemination to communities involved, such a local talks and press briefings, are important to acknowledge those involved and strengthen relationships with key prior, and possibly future, contributors.

## 6.5.18 Key messages

- **Preparation is critical to ensuring that research in the field is effective, safe and contextually appropriate. This includes obtaining the necessary administrative and ethical approvals, preparing protocols and standard operating procedures, as well as careful planning in regard to equipment, data security and logistical questions.**
- **Security and safety in the field is paramount and should be considered before and during field work. Training courses are available in this.**
- **It is important to develop a good relationship between researchers and the community; this can be achieved by demonstrating reliability and communicating the value of the research to the community.**
- **Review ethical approvals and in-country protocols for research and follow any policies requested in these. Using agreements and protocols can ensure clarity as to roles and responsibilities. Adhere to standard operating procedures. Document all decisions and the rationale used to make them.**

## 6.5.19 Further reading

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# 6.6 How to write up your research

## Authors

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## 6.6.1 Learning objectives

To understand the practical steps involved in preparing a report of your research, including:

1. Identifying and targeting the relevant audience for better impact, use and uptake of your research findings.
2. Prioritizing what needs to be in the manuscript and identifying an appropriate journal.
3. Preparing an outline of the manuscript.
4. Developing the manuscript in accordance with the guidelines of the targeted journal and relevant reporting guidelines.
5. Getting the manuscript accepted and published.

## 6.6.2 Introduction

The foremost priority in health emergency and disaster risk management (Health EDRM) is serving and saving the lives of affected people. However, priorities change at different phases of the emergency cycle: prevention, preparedness, response and recovery. Public interests of safety, survival and well-being take precedence over research interests in the acute phase of emergency response (1). Nevertheless, it is important to conduct research, while making best use of available time and resources, in order to improve Health EDRM practices (2). It is also then vital that this research is made available to others, which usually means publication in an appropriate scientific journal.

Conducting research in an emergency setting is not an easy task, amidst competing and fast changing priorities. The findings of such research are therefore precious and worth reporting – provided they add and further inform the existing body of literature. Earlier chapters have shown you how to design and conduct a research study; this chapter takes you through the processes involved in synthesizing research findings in such a way that they are accepted as scientific evidence. It describes some generic steps that you can follow to prepare your manuscript and get it published in an appropriate journal.

### 6.6.3 Choosing a journal

The first step in preparing a report of your research is to think about and decide on the intended audience or readers of your report. If you have focused your research work on emergency preparedness and response, or any other specific subject pertaining to Health EDRM, then you would like professionals who work in this area to know about your research results.

There are tens of thousands of scientific journals online. However, around 80 journals focus on disasters, hazards, risks, emergency management, response and humanitarian issues. Some are peer-reviewed journals that are indexed in bibliographic databases, such as those mentioned in Chapter 6.2, while others are non-indexed journals. Indexed journals are generally considered to be of higher scientific quality than non-indexed journals *(3)*, and their content will be more easily retrieved by people searching the bibliographic databases. Furthermore, if you want to ensure a wider audience for your research, you should choose an open access journal, which will allow unrestricted distribution of your research article. If your research received external funding, then those funders might also prefer that it should be published open access, to influence a wider audience. However, open access journals usually ask for publication charges and if you do not have the funding, it may be difficult to get a place in such journals despite the quality of your report.

In choosing a journal, you should look at the editorial team to give you an idea about its composition, including whether its members are drawn from a specific region or from across the world. Look for the specific themes that the journal focuses on and consider how your research will fit with these. Looking at the types of articles published by the journal in recent issues will give you an idea of whether your research falls within the scope of the journal.

It takes dedication, time and hard work to do research and come up with research evidence, so the report of that research should be able to find a place in an indexed journal with a good impact factor. This will give it a higher probability of being noticed, cited by others and translated into practice by policy makers, administrators, practitioners and other stakeholders. The impact factor is an indicator of the prestige and popularity of the journal *(4)*: the higher the impact factor, the more competitive the process of acceptance of a manuscript in that journal will be. Be mindful of your ambitions in targeting a journal according to their impact factor. You should try to have an objective assessment of the quality of your research. Usually, high-quality research can be submitted to a high impact factor journal, but a lower quality study will usually have a higher chance of being accepted by a journal with a low impact factor. If the research findings are meaningful only for a local setting or single country, it might be better to target a national journal, even if it has a comparatively low impact factor.

Check the authors' guidelines from your chosen journal carefully – you will need to follow these instructions for structuring your manuscript. It is vital that you format your manuscript (headings, subheadings, citations, references and so on) consistently, correctly and in compliance with the style of the journal. This is a sign of professionalism that editors and reviewers note and appreciate. Do not forget to check the submission and review process for the journal. It is helpful to know how much time the journal is likely to take from receiving your manuscript to its review and, if accepted, final publication. Some journals complete their review process within weeks, while some may take many months. The speed of the process depends on the willingness of potential referees to review a manuscript. A correct title and a good abstract will increase the likelihood that referees will want to review the paper. A poorly written abstract and an ungrammatical title may dramatically reduce this likelihood. Review by scientific peers can be an open or closed process and you should decide based on your preferences.

Despite all your hard work on your research study and description of its findings, sometimes a journal may decide not to publish your manuscript. As a backup plan, identify an alternative journal that you may consider submitting your manuscript to, in case you need to switch from your first choice.

### 6.6.4 Plan writing up your research

A clear understanding of what and how you want to publish, whom you want the findings to reach and how it will be translated into practice will provide you with a good orientation and context for writing about your research. Writing style, the amount of contextual information you provide and how you present your findings may vary according to your target audience.

To keep yourself focused, write down in one or two paragraphs the main points as to how your research adds value to existing work and the recommendations it lead to for the future. This will help you to summarize your work as a ‘conclusion’. It can also help if the journal wants you to provide details on why your research work is important.

As discussed in other chapters, when doing and reporting your research, you should do so in a spirit of transparency, objectivity, honesty and equal opportunities for all. Local people who helped should be given the opportunity to get involved fully in doing and synthesizing findings of the research. There should be a clear understanding among all those involved about who will be an author and the sequencing of authorship, which might be based on the actual contribution to the study. In deciding the order of authors on the manuscript, the researcher who has conceptualized the research and prepared the first draft of the manuscript is likely to be listed as the first author. Traditionally, the last author will be the person who closely supervised the research, mentored the team or provided key advice in finalizing the manuscript, but this is not always the case.

Depending on the scope of your research (for example, whether it focused on one issue or more than one), you, your colleagues and other stakeholders involved in the research can decide whether to present all the findings and analysis in a single, major publication or to split the work across more than one article, with each focusing on a different topic.

### 6.6.5 Choose a title

The title of the manuscript should be short, grammatically correct and reflect the essence of the research. It should be phrased in such a way that it catches the attention of readers and gives them a clear indication of what the research article contains. Follow the journal's guidelines on the style of the title, which may also include stating the study design.

### 6.6.6 Outline and develop your manuscript

Various guidelines exist for the preparation of reports for a wide range of types of research study. Many of these reporting guidelines have been collated by the Equator Network and are listed on their website (www.equator-network.org). You should follow the relevant reporting guidelines when preparing your manuscript. For example, there are the STROBE guidelines for observational studies *(5)*, the CONSORT guidelines for randomized trials *(6)* (Chapter 4.1), the PRISMA guidelines for systematic reviews *(7)* (Chapter 2.6), and RECORD guidelines for studies using routinely collected health data *(8)* (Chapter 2.4), among many others. Table 6.6.1 shows the usual structure of a research manuscript, regardless of the study design.

**Table 6.6.1 Structured outline of a scientific manuscript**

| |
|---|
| Title |
| Authors' names with their affiliations |
| Corresponding author with contact details |
| Abstract |
| Key Words |
| Introduction and/or background |
| Materials and methods |
| Results |
| Discussion |
| Conclusion |
| Acknowledgements |
| Conflicts of interest |
| References |
| Annexes and supplementary material |

**Introduction and/or background:** This section should demonstrate your awareness of the problems or issues, existing research, possible solutions and best practices on the topic. Highlight the identified problems or gaps that necessitated your research. Provide an overview of the context of your research for readers of your article. If you quote data or phrases from other papers, always cite these sources and do so in the style recommended by the intended journal. Statements of fact that you make in the report should be supported by the relevant evidence and references. You should state the objectives of the study in the last paragraph of this section.

**Materials and methods:** Write a succinct description of the methods you used to conduct your research. Be meticulous and accurate *(9)*. Readers will be interested in knowing what the research design was and who the participants or subjects of the research were. If you are writing a review article, mention the research databases that you searched, including the terms used and any restrictions by language or publication year. If ethics approval was required, this should have been obtained before the study started (Chapter 6.4) and, if so, this should be explicitly mentioned in the manuscript.

**Results:** In this section, you should objectively present data, facts and observations from your research, along with brief interpretation. Quantitative data might be summarized in tables and graphs, with data to show the imprecision of the analysis (such as statistical significance and confidence intervals) (Chapter 4.2). Always keep in mind the intended audience of your report when deciding on how to present your findings. Always remember that null or negative results can be just as important as positive results to let others know that interventions are ineffective or harmful, or that associations do not exist between variables. Presenting important results graphically may garner more attention, but the number of tables and figures allowed in a report is usually limited by the journal and you must comply with its guidelines. Details about your methods or your interpretation of the results should not go in this section, but should go into the Discussion section.

**Discussion:** The findings and main observations relating to your research question and study objectives should be discussed in this section, along with what is already known on the topic. The section should not merely repeat your results or the information you provided in the introduction section. Rather, it should be written to provide readers with clarity on how the findings of your research support the arguments you develop for discussion. Avoid statements that are not supported by the findings of your research or other evidence. If there are limitations in interpreting and applying your research findings, be self-critical and describe these limitations so that readers can be cautious when interpreting your results and inferences. In addition to describing the limitations, you can also highlight the advantages of the research you conducted. If you think it would be helpful to highlight key learnings from your research (and this is acceptable to the journal), write these in bullet points in a box with an appropriate title.

**Conclusions:** This section should summarize your findings and key inferences and provide direction for future practice and further research in the topic area. It should provide a clear, simple and crisp message to show how the research will be useful and influence practice and policies. It is usually best to keep this section to a few paragraphs or less and, in some journals, it can be the last paragraph of the discussion section.

**Acknowledgements:** Remember to acknowledge those who participated in your research work, funded the study or who helped you prepare the report.

**Conflicts of interest:** All authors should declare any conflicts of interest relating to the conduct and publication of their research findings. If there are none, write something such as ‘No known conflicts of interest’. This transparency helps readers to ascertain the objectivity of the statements you make in your research article.

**References:** You should list all references mentioned in the text of the manuscript in the style required by the journal, so check their guidelines again. There are multiple referencing styles but two of the most common are:

- *Harvard style*: this is also known as 'author-date style'. The in-text call out or citation is usually shown in brackets in the body of the text or in footnotes. Full details are listed in alphabetical order in the reference list.
- *Vancouver style*: this is also known as 'numeric referencing style'. Each in-text call out or citation is shown as a number, which corresponds to the order it appears in the text. If the same source is cited more than once, the same number is used. References are then listed in numeric order in the reference list.

Only relevant evidence and information should be quoted in the text and listed in the references, so that interested readers can check the quoted argument, statement or data.

**Annexes and supplementary material:** Tables or graphics that you want to include in the text are usually placed at the end of the manuscript you send to a journal. The journal then places these in the correct place if they accept it, and before publishing the report. Some journals also allow you to provide supplementary material for the manuscript, which might be published alongside it on the journal website *(10)*. Some journals also provide data repositories and hyperlinks or might require you to provide links to the data on which study is based.

**Abstract:** Having written the full manuscript, including your conclusions, you should be very clear about the key things to put into a summary of that main text, which would become its abstract. A common error in writing an abstract is to make it an introduction, when it should be a summary. The usual structure of an abstract is similar to that for the article itself: background, methods and materials, results and conclusion. An abstract is usually around 250 words long *(11)*. Together with the title, it will act as an advertisement for the article's content and, if the article is included in a bibliographic database, the abstract should help readers to find your research and decide whether to read the full paper. So, make the abstract simple, interesting and informative, without using technical jargon and abbreviations.

**Key words:** The journal might also ask you to provide some key words to make it easier for people to find your research article. Choose key words that capture the essence of your research (for example, if you are writing about health emergency and disaster risk management, use words such as risk management, and disaster risk reduction or DRR).

As you start writing these sections of your manuscript, we hope that you will find that your words start falling into place. It is always better to write with your original thoughts. In preparing a first draft, do not worry too much about the exact phrasing or the word limit of the journal. Instead, keep writing, making sure that you consider relevance, coherence and the applicability of your research findings.

Share the first draft with your co-authors for their input. This may lead to a series of revisions and further draft versions before it becomes your finally agreed manuscript, which will need to be within the word limit for the target journal. This step is important because all authors involved need to be willing to take responsibility for the submitted manuscript. You might also want to share the almost final version of the manuscript with other colleagues or friends for proofreading, in order to help ensure that it is clear to them and to pick up anything that needs correcting before it goes to the journal. However, if you share the manuscript outside the author team, you need to be clear that they must not disclose the findings or pass the manuscript to anyone else without your permission. When you receive comments and suggestions from your colleagues or friends, do not ignore them. Consider them carefully because if they had difficulty in understanding some text, the journal editors, peer reviewers and eventual readers of the article will probably also have difficulties with it.

One valuable tip is to keep a print copy of the final version on your desk for at least one week before submitting it. Engage yourself in other activities and try to forget about the manuscript. Then when you return to it, you might identify ways to improve it further with a fresh eye.

### 6.6.7 Seeking clearances for your manuscript

Depending on your employment status or the practices of the organization or institution that you work in, you may need to obtain administrative clearances and approval from your department. You may also need to obtain formal approval from those that were involved in your research study, if you do not already have this. In some cases, this may require approval from a government department in the country where the research was done. It is important to get this if you need it, and it may be helpful to involve someone from the relevant department in the author team. This has the added advantage of building local research capacity as well as receiving faster approval. Likewise, you should mention the name of any ethics committee that approved your research (see Chapter 6.4) and share a copy of the manuscript with it, if required.

It is a common misconception that editors are responsible for copyright clearance. This should be sought from authors and publishers. The latter may have systems on their websites to make the process easy. Reuse of diagrams, data and long quotations requires copyright clearance to be obtained from publishers, even if the material was the author's own. However, material published under Creative Commons licenses requires only citation of the author and origin of the work.

### 6.6.8 Submitting your manuscript

Your manuscript is now ready for submission to your intended journal. However, merely submitting it to a journal is not enough to get it published. It will be reviewed by the journal editorial team and your peers. As you submit it, most journals will require all the authors to sign a statement taking public responsibility for the content in their manuscript. One of the authors will also need to be identified as the corresponding author. Although this is usually the first author, it might be another co-author who has been engaged in the research and will be able to answer questions about it.

If the journal is sufficiently interested in your manuscript, they will probably send it to one or more peer reviewers. Some journals will do this after removing the names of the authors and their institutional affiliations. You should be ready to respond to any comments provided by the peer reviewers. You will be expected to address the issues raised by revising the manuscript and responding to any suggestions for changes. Be polite and respectful when you respond, even if you disagree with a reviewer's comments and have not acted on them. Provide clarification if they misunderstood a point or provide additional information if necessary. If you feel that a reviewer's criticism is unfair, or some of the suggested amendments in the manuscript are unwarranted, you have right to make a representation to the editor and set out a rationale for not following the reviewer's instruction. The revised manuscript should be re-submitted to the journal, usually with a detailed response to each of the comments from the editors and the peer reviewers.

In some cases, the journal may tell you that it will not be considering your manuscript for publication. There is no need to feel discouraged. This does not necessarily mean that your research and manuscript are not worth publishing; sometimes, journals have their own focus or plans for upcoming issues that your manuscript does not fit with. Whatever the reason, consider any comments from the editors and peer reviewers carefully, revise the manuscript if you wish to and submit it to an alternative journal.

### 6.6.9 Finalizing your manuscript and publication

When a journal confirms that your manuscript has been accepted for publication, the editorial team will send you a formatted version, showing how it will look in the journal, and may ask for some further clarifications or changes. This version of the manuscript is often called the "proofs" and it is your last chance to check the manuscript for any errors before it is published. You will usually be given only a few days to respond, so check it carefully and quickly, and reply to the journal with necessary adjustment of any formatting or typing deficiencies and correction of the proofs. The more accurate the final submitted manuscript is, the fewer the corrections that will be required at the copy-editing and proof stages.

### 6.6.10 Conclusions

Generating, doing and reporting research – especially research relating to Health EDRM – makes an important contribution to the improvement of the health of people at risk. It should be well planned and conducted in a systematic way. Research is considered complete once it can be used by the stakeholders and policy formulators, and when its recommendations start being translated into actions. This will only happen if the research is fully and clearly reported, and if a research article reporting the research is accessible to those who need it.

## 6.6.11 Key messages

- **Preparing and publishing findings of research relating to Health EDRM is a valuable contribution to strengthening the humanitarian development nexus.**
- **Be clear about the new evidence you have generated and how it can make a positive difference.**
- **Prepare your manuscript in accordance with the guidelines for authors of the chosen journal, the relevant reporting guidelines for the type of study you did and the expectations of your target audience.**
- **Ensure that the final version of your manuscript gives a clear account of the research that will be understandable to readers.**
- **Ideally, submit the manuscript to an open-access journal, which will ensure its wide distribution, use by others and uptake of your findings.**

## 6.6.12 Further reading

Booth WC, Colomb GG, Williams JM. The craft of research (2nd edition). Chicago, USA: University of Chicago Press; 2003.

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### 6.6.13 References

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# 6.7 Doing research in Health EDRM

## Author

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## 6.7.1 Learning objectives

To understand key factors to consider when doing research in health emergency and disaster risk management (Health EDRM) and be able to:

1. Outline the main purpose of doing research in Health EDRM.
2. Explain various aspects that influence the choice of the topic to investigate, and the characteristics that this topic must have.
3. Discuss the contrasts between the approaches of systemic disaster risk with those of the environmental approach to health associated with biological risks.
4. Explain the importance of the Theory of Change and an Evidence-based Research Strategy, and why they can be complementary to research in Health EDRM.

## 6.7.2 Introduction

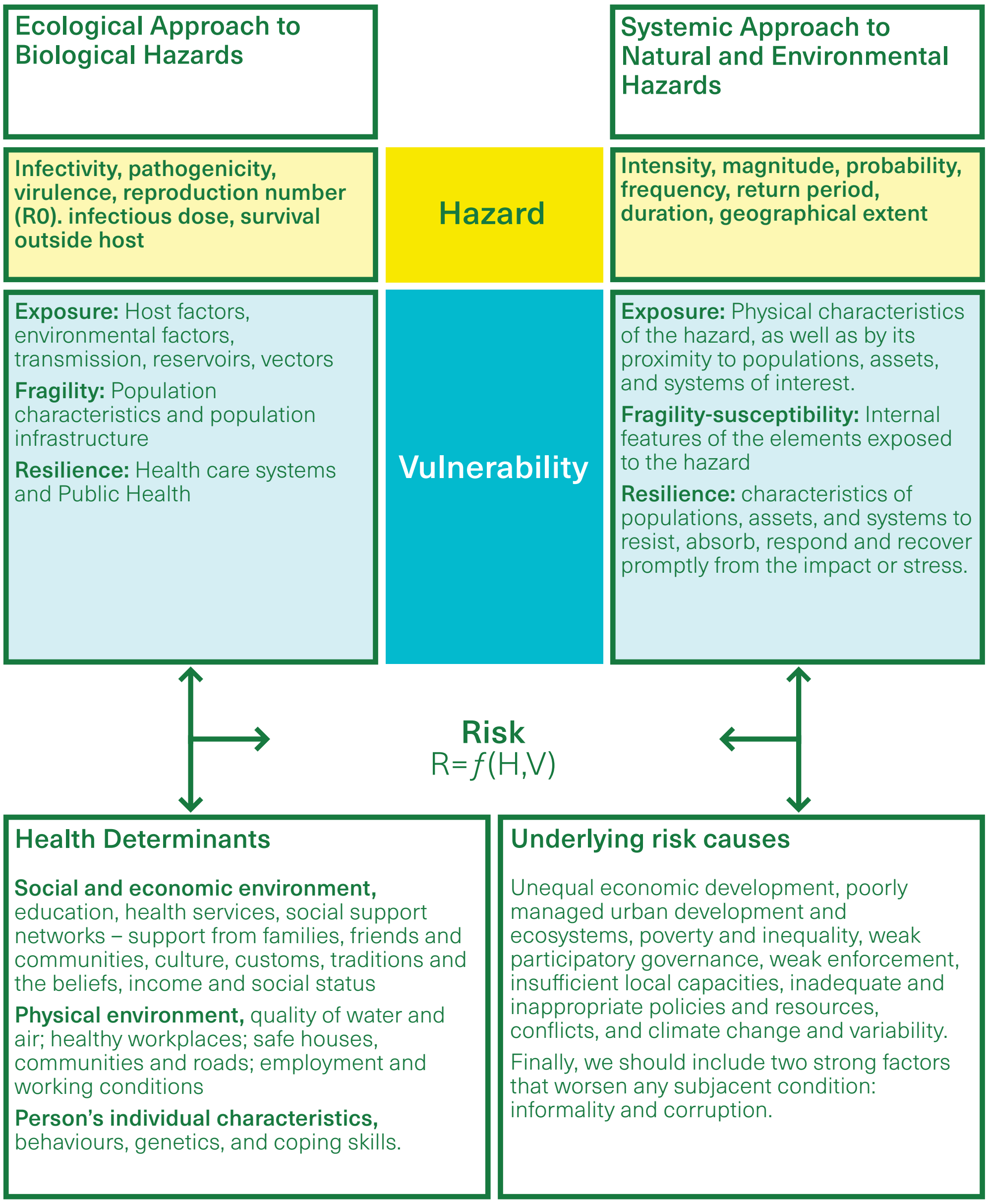
Conducting research in Health EDRM presents unique and diverse opportunities, given the complexities of the concepts of health, risks and disasters described throughout this book. The main purpose of Health EDRM research is to generate high quality knowledge that can be used to promote, restore and maintain the health status and health equity of individuals and communities exposed to disaster risk, or during and after emergency or disaster situations.

This chapter has been organized around five questions: What? How? Where? When? and Who? Each is important to conducting research in the field, highlighting issues described in more details in other chapters of this book. ‘What?’ refers to the choice of research topic (Section 3); ‘How?’ refers to the approach or strategy to be used as well as the methodologies and technologies to be followed (Section 4); ‘Where?’ raises the question of the geographical scope and coverage of the study;’ When?’ covers the considerations of time in the study; and ‘Who?’ helps to identify the target audience, the research team, and other actors directly or indirectly involved in the study.

### 6.7.3 The research topic – what?

Choosing the topic to investigate is conditioned by aspects such as curiosity, health needs, research gaps, benefits or opportunities that arise. The selected topic must be feasible, interesting, novel, ethical, and relevant *(1)*. Selecting the topic means answering the question of what to investigate. To visualize possible research topics, Figure. 6.71 contrasts an ecological approach to risks to health associated with biological hazards with the systemic approach, drawing on concepts of hazard, vulnerability and risk.

**Figure 6.7.1. Ecological approach to biological hazards** *(2).*



Ecological Approach to Biological Hazards

**Infectivity, pathogenicity, virulence, reproduction number (R0). infectious dose, survival outside host**

**Exposure:** Host factors, environmental factors, transmission, reservoirs, vectors

**Fragility:** Population characteristics and population infrastructure

**Resilience:** Health care systems and Public Health

Systemic Approach to Natural and Environmental Hazards

**Intensity, magnitude, probability, frequency, return period, duration, geographical extent**

**Exposure:** Physical characteristics of the hazard, as well as by its proximity to populations, assets, and systems of interest.

**Fragility-susceptibility:** Internal features of the elements exposed to the hazard

**Resilience:** characteristics of populations, assets, and systems to resist, absorb, respond and recover promptly from the impact or stress.

Health Determinants

**Social and economic environment,** education, health services, social support networks – support from families, friends and communities, culture, customs, traditions and the beliefs, income and social status

**Physical environment,** quality of water and air; healthy workplaces; safe houses, communities and roads; employment and working conditions

**Person's individual characteristics,** behaviours, genetics, and coping skills.

Underlying risk causes

Unequal economic development, poorly managed urban development and ecosystems, poverty and inequality, weak participatory governance, weak enforcement, insufficient local capacities, inadequate and inappropriate policies and resources, conflicts, and climate change and variability.

Finally, we should include two strong factors that worsen any subjacent condition: informality and corruption.

This visualization highlights convergences and specificities in the two approaches, creating a rich analysis framework that can be used to select topics, relationships, factors and contexts that can be considered in Health EDRM research.

### 6.7.4 Approach or strategy – how?

Two approaches in particular facilitate the approach to the problem to be solved: the Theory of Change (Chapter 4.10) and the Evidence-based Research Strategy (Chapter 3.6). The Theory of Change is an approach aimed at planning and evaluating social change interventions, going beyond the association between an intervention and its outcome, looking for ways to acquire knowledge about causation, context and assumptions *(3)*. The Theory of Change allows problems to be associated with goals, identifying trajectories, domains of change, fundamental elements to define what should be evaluated, focus on key information, and prioritize what really needs to be known and why.

The Evidence-based Research Strategy is the systematic use of previous research to inform a new study so that it answers key questions about effectiveness, efficiency, accessibility and sustainability *(4)*. Sarmiento *(5)* identifies seven stages for the design of an evidence-based research strategy:

i. identify relevant interventions
ii. prepare evaluation questions
iii. select evidence sources and implement a search strategy
iv. appraise evidence and identify gaps
v. create and implement evaluation design
vi. apply the evidence
vii. evaluate the evidence application.

Case Study 6.7.1 shows how an evidence-based research strategy was used by WHO to establish the state-of-the-art guidelines for risk communication for public health emergencies.

### Case study 6.7.1
### Communicating risk in public health emergencies: A WHO guideline for emergency risk communication policy and practice

Recent public health emergencies, such as the Ebola virus disease outbreak in West Africa (2014–2016) and the emergence of the Zika virus syndrome in 2015–2016, have highlighted major challenges and gaps in how risk is communicated during epidemics and other health emergencies. The challenges include the rapid transformation in communications technology, the widespread use and increasingly powerful influence of digital media and its impact on 'traditional' media (newspapers, radio and television), resulting in changes in how people access and trust health information. Existing gaps include considerations of context – the social, economic, political and cultural factors influencing people's perception of risk and their risk-reduction behaviours.

Although there were already principles, good practices and training in the area of emergency risk communication, there was no comprehensive evidence-based WHO guidance on this topic. In 2015, WHO prepared comprehensive evidence-based guidance on how risk communication should be practiced in crisis, emergencies and disasters *(6)*. The guidance also provides the best approaches for strengthening emergency risk communication capacity and sustaining this for potential health emergencies.

These guidelines were preceded by the definition of twelve research questions, covering trust and community participation, integrating emergency risk communications into health and emergency response systems, and emergency risk communication practices. These questions were developed in terms of potential searches, using the SPICE Framework (Setting, Perspective, phenomenon of Interest, Comparison, Evaluation of impact) and were used to guide systematic reviews of the existing literature by different institutions.

The Theory of Change and the Evidence-based Research Strategy approaches are not mutually exclusive. They complement each other, particularly when multiple interventions need to be assessed for effectiveness, efficiency and sustainability. In some cases, studies on Health EDRM require more process-oriented and short-term results, in which the actors involved use common methods such as case studies, lessons learned and good practices. Studies using these methods have some analytical limitations, remaining descriptive at best, and few reach the level of theoretical, indicative or causal analysis *(7)*.

Case studies in health can have different approaches and are widely used in Health EDRM. In fact, there are numerous studies that have become important references for academia, institutions and practitioners. A case study is a research strategy and an empirical inquiry that investigates a phenomenon within its real-life context. There are four different types of case studies: illustrative, exploratory, cumulative, and critical. Illustrative case studies are considered descriptive and are designed to elucidate a particular situation. Exploratory case studies are used to identify research questions and methods for complex study. Cumulative case studies correspond to a compilation of case studies already completed on a specific topic. Finally, case studies of critical cases are used to understand what happened with a single event or challenge *(8)*.

### Lessons learned

Lessons learned can be defined as knowledge or understanding gained through experience or reflection on a process. This experience or process can be positive or negative. In order to be relevant and useful, 'lessons learned' must be:

- Applicable, because they have actual or potential impact on operations or processes.
- Valid, because they are based on facts.
- Significant, because they identify processes or decisions that reduce or eliminate failures or reinforce positive outcomes.

Lessons learned help to (i) identify success factors (effectiveness, efficiency, sustainability); (ii) identify gaps (shortcomings) in policies, strategies, programmes, projects, processes, methods and techniques; (iii) identify and solve problems through new courses of action; and (iv) improve decision making and serve as a model for other interventions.

Case Study 6.7.2 shows the application of the lessons learned methodology on the health response after the 2010 earthquake in Haiti.

#### Case study 6.7.2

#### Health Response to the Earthquake in Haiti, January 2010: Lessons to be learned for the next massive sudden-onset disaster

After the January 2010 earthquake in Haiti, the Pan American Health Organization/WHO prepared a report about the health effects of the earthquake and the effectiveness of national and international health relief efforts *(9)*. The magnitude 7.0 earthquake had a devastating impact, leaving more than 220 000 dead, over 300 000 injured and 1.3 million forced into temporary shelters. This catastrophic outcome was the result of both socioeconomic and seismic factors: the vulnerability of Haitian housing and construction, the shallow hypocentre of the earthquake, and its proximity to the country's most important urban centre. Rural areas in the West and South-East departments were also badly affected.

The report indicates that Haitians themselves responded swiftly and effectively, saving many lives before foreign help could arrive. However, the domestic response was severely limited by the destruction of the country's capital and the impact on government staff and facilities. The international community responded quickly and with solidarity, including not only the traditional donor nations, but practically all the Latin American and Caribbean countries. Unfortunately, the response showed the same chaotic tendency as in past disasters: insufficient information, improvised decisions not based on evidence, and a marked lack of sector coordination. The health emergency and disaster risk management problems recorded in previous events were repeated and even amplified in Haiti. The humanitarian community could not put into practice the lessons learned, and that is why the subtitle of report says: "Lessons to be learned for the next massive sudden-onset disaster."

**Good practices**
Good practices can be defined as efficient solutions to solve or tackle a problem. These practices have been validated through extensive use, obtaining positive outcomes in various contexts, which are confirmed by evaluations. In short, 'good practices' are those that:

- have been implemented with proven effectiveness
- can be replicated and applied in different contexts achieving similar results
- have met or exceeded the expected objectives and have delivered the expected outputs
- are sustainable over time.

### 6.7.5 Geographical scope, scale, and coverage – where?

An indispensable aspect to consider when planning Health EDRM research in the field is the geographical scope and the coverage that is intended to be achieved. Territory and health are intrinsically linked. The spatial context affects the configuration of environmental risks, as well as influencing other health effects. Social, built and natural environments affect health and well-being in ways that are directly relevant to health research. The geographical scope, scale and coverage sought in a health study should be directly related to the available resources, as well as the expected specificity and depth.

A study about underlying risk factors of local communities in Chile *(10)* illustrates a type of research on risk factors (Chapter 3.2) or social determinants of health with a particular focus on disaster risk. The study includes 60 municipalities (20% of total municipalities in Chile), encompasses 41 variables grouped in four categories: governance, territorial planning, socio-economic and demographic conditions, and climate change and natural resources. Using a multicriteria statistical processing method, the study captured the different features that shape vulnerability and guide effective disaster risk management at the local level. Studies such as this one reflect the importance of identifying and measuring the physical attributes of the territory at different scales, as well as the qualitative attributes, such as poverty and governance, that contribute decisively to constructing the vulnerability of individuals and communities.

### 6.7.6 Time considerations – when?

Cross-sectional studies analyse the situation or conditions at a given time (for example, a study on the health impact of the population exposed to the violent eruption of a volcano), while longitudinal studies or cohort studies follow the same sample of people over time (for example, a study on the evolution of the population health conditions chronically exposed to volcanic activity). Another view of the time factor in health research can be observed when addressing aspects associated with different stages of emergency and disaster management: before, during, or after an adverse event. It could also include studies in prospective risk management as a particular consideration of time in the study. In this case, stochastic modelling methods are used to explore possible future scenarios, which may or may not have statistics or historical records (for example, epidemics generated by unknown germs, technological accidents, and cyber-attacks).

Other less frequent approaches to the time factor in research include retrospective studies which look backward and examine exposures to suspected risk or protection factors in relation to an outcome that is established at the start of the study (for example, a retrospective study of acute health effects due to volcanic ash exposure during a volcanic eruption).

### 6.7.7 Study stakeholders – who?

The stakeholders of a study include the target audience, the research team, partners, alliances and people and institutions who might be involved in the design and implementation of the study.

Research in Health EDRM generates scenarios conducive to the performance of interdisciplinary groups, as well as alliances between different research groups. According to WHO *(1)*, health research traditionally contemplates the involvement of three categories of sciences:

- biomedical sciences (such as biological, medical and clinical research, and the generation of biomedical products)
- population sciences (such as epidemiology, demography and socio-behavioural)
- health policy sciences (such as research in health policy, health systems and services, and population health).

In Health EDRM, other science categories have a clear role, particularly those associated with natural hazards: earth sciences (such as geology, meteorology, oceanography, and astronomy). The scope of the research ranges from biomedical research, epidemiological studies, health services research, perception and behaviour studies, community assessments and social, cultural, environmental and economic risk factors that directly affect health.

Case Study 6.7.3 describes a study on climate variability and climate change, and its effects on human health *(11)*. It illustrates how research can influence practice or policy.

### Case Study 6.7.3

### The impacts of climate change on human health in the USA *(11)*

This extensive study is the result of the work of several interdisciplinary teams composed of more than 100 experts from eight US Federal agencies (including employees, contractors, and affiliates). It was subject to a rigorous peer review process by public and scientific experts inside and outside government, including a special committee of the US National Academies of Sciences, Engineering and Medicine.

The study investigated how climate change is already affecting human health and the changes that may occur in the future. The objective is to provide a comprehensive, evidence-based and, when possible, quantitative estimate of the health impacts related to climate change observed and projected in the USA.

The report does assess scientific literature describing the role of adaptive capacity in creating, moderating, or exacerbating vulnerability to health impacts where appropriate. The report also cites analyses that include modelling parameters that make certain assumptions about emissions pathways or adaptive capacity in order to project climate impacts on human health. This scientific assessment of impacts helps build the integrated knowledge base needed to understand, predict, and respond to these changes, and it may help inform mitigation or adaptation decisions and other strategies in the public health arena.

According to the study, as the climate continues to change, the risks to human health will grow, worsening existing health hazards resulting in new public health challenges (for example, increases in human exposure; excessive heat; more frequent, severe or longer-lasting extreme weather events; degraded air quality; foodborne, waterborne, and vector-borne diseases). Some special populations of concern, such as children, the elderly, outdoor workers and those living in disadvantaged communities, will be more vulnerable.

The document not only seeks to inform public health officials and professionals in the health sector, but also aims to reach out to urban planners, disaster risk and emergency managers, decision makers, as well as others within and outside the government who are interested in better understanding the risks that climate change presents to human health.

## 6.7.8 Conclusions

Overall, research in Health EDRM has to take an interdisciplinary approach, integrating the natural, social, and health sciences to look at as many direct and indirect factors as affect health. Existing frameworks and theories can guide the process to anticipate, understand, and formulate a conceptual construct geared to the formalized design and development of field research, especially to answer the five questions (what, how, where, when, and who) when planning the study. Choosing which research approach to implement depends on many things, including the local risk and health factors, available resources, applicability and allotted time. It is also important to consider how the research will be presented afterwards such as publications, policy briefs, and dissemination back to the research community.

## 6.7.9 Key messages

- **The main purpose of Health EDRM research is to generate high quality knowledge that can be used to promote, restore and maintain the health status and health equity of individuals and communities exposed to disaster risk, or during and after emergency or disaster situations.**
- **Health EDRM research requires an interdisciplinary vision.**
- **The ecological approach to health and systemic disaster risk approach generate a broad space for research in disaster risk management and health emergencies.**
- **The Theory of Change and the Evidence-based Research Strategy complement each other, particularly when multiple interventions need to be assessed for effectiveness, efficiency and sustainability.**

## 6.7.10 Further reading

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