EUROCARE STEERING COMMITTEE MEETING
29 January 2015
Fondazione IRCCS " Istituto Nazionale dei Tumori", Milan, Italy

Participants: Franco Berrino (Chairman), Gemma Gatta, Roberta De Angelis, Silvia Francisci (EUROCARE direction), Mats Lambe, Magdalena Bielska Lasota, Maja Primic Žakelj, Nadine Bossard, Pascale Grosclaude (substituting Marc Colonna), Michel Coleman, Riccardo Capocaccia, Alexander Katalinic, Rafael Marcos Gragera, Paolo Baili (EUROCARE SC members), Camilla Amati (EUROCARE secretariat).

Regrets: Milena Sant, Jean Faivre, Julia Verne, Renée Otter; Marc Colonna

Auditors (EUROCARE researchers)**:** Laura Botta, Annalisa Trama, Silvia Rossi, Sandra Mallone, Daniela Pierannunzio, Andrea Tavilla, Hade Amash, Paolo Roazzi

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F. Berrino: Meeting Introduction

- Welcome to N. Bossard, for the first time at the EUROCARE Steering Committee
- Welcome to P. Grosclaude, substituting M. Colonna for FRANCIM
- Last three EUROCARE rounds central data collection and analysis were subsidized by the Italian Bank Foundation "Compagnia San Paolo"
- The EUROCARE coordinating group is now formed by R. De Angelis, S. Francisci from ISS in Rome and M. Sant and G. Gatta, from INT in Milan
- The last project subsidized by "Compagnia San Paolo" will close in 2015 and for this reason the idea is to launch the EUROCARE-6 call in 2015.

It is an aim of the European Union to establish a European Cancer Information System. In this framework, the Joint Research Centre in Ispra will collect raw data from Cancer Registries through the ENCR (European Network of Cancer Registries). (There is no restriction with respect to EFTA/EEA countries). The EUROCARE secretariat convened the SC with the purpose of discussing the EUROCARE-6 protocol and call management.

C. Amati (substituting M. Sant)
Update on EPAAC results, JRC activities, EUROCARE and JRC-ENCR collaboration
The achievements of the European Partnership Action against Cancer (February 2010- February 2014) are accessible in the EU Report of 23.09.2014. As part of the EPAAC's WP9 activities, EUROCARE-5 survival estimates were published, New European High Resolution studies were launched, the status of cancer information in Europe was reviewed and we coordinated the European Cancer Information System proposal (ECIS) for a strategic re-organisation of the data and information flow, to make more effective use of cancer information data in agreement with all the relevant stakeholders. The ECIS work served as a basis for JRC activity on cancer information, as from December 2012 the centre was charged to sustain the European work on cancer information (hosting ENCR secretariat, promoting standardization of data collection, training courses, updating old CR recommendations and hosting a unique gateway for CRs). On 5 December 2013, a MAC (Members of Parliament Against Cancer) roundtable was organised at the European Parliament on EUROCARE: this was the occasion for the launch of the EUROCARE-5 summary papers. On 12 February 2014 the European Parliament's Committee on Environment, Public Health and Food Safety (ENVI) organised the workshop "Harmonisation and centralisation of cancer data, data

protection" on the topic of the European Cancer Information System. In this context, three workshops on "Quality Checks for analysing cancer registry data: development of one common procedure" (involving ENCR, EUROCARE, CONCORD, IARC, JRC) were hosted by JRC, Ispra on 02.07.2013, 15.10.2013 and 04.06.2014 with the following aims:

1. improving and harmonizing cancer registry data collection and quality checks with the final objective of a common call for incidence, survival and prevalence data;
2. harmonising the process of quality checks of cancer registry data as the basis for development of a web-based tool;
3. a review of quality check procedures currently in use.

The report was launched at the ENCR General Assembly in November 2014 and is available here. The EUROCARE met with ENCR-JRC on 12 December 2014, a collaboration for the EUROCARE-6 data call in the ENCR call 2015 was agreed and regular contact between the EUROCARE group and a dedicated ENCR "protocol and data call" working group is foreseen during February 2015. (for time plan and variables, see below).

EU Data Protection Regulation

A proposal for a regulation on data protection was issued on 25.1.2012. (A "regulation" is a law valid in every EU Member State. By contrast, the 1995 Directive on data protection must be implemented in national law within three years by each Member State separately). It is therefore particularly important that the new Regulation does not restrict public health research, because it will become law in all 28 Member States at once when it does come into force. Articles 81.2 and 81.3 in the draft Regulation are especially problematic. Final decisions will made this year. In December 2013, the EUROCARE-MAC roundtable highlighted the need for Member States to ensure that public health research, specifically conducted on the basis of population-based disease registries, is not impeded by the new proposal on a General Data Protection Regulation. EUROCARE confirms its support to cancer registry activity. Public health research shall be granted with an exemption from consent for the patient registries, in order to (i) permit the collection of complete, accurate and high quality data, (ii) to develop effective evidence-based policy decisions, and (iii) to measure effectiveness of the latest. Specific EUROCARE actions may be discussed.

R. De Angelis

EUROCARE-6 protocol discussion and decisions

EUROCARE goals are to contribute to:

- Increase standards of cancer care in Europe
- Reduce inequalities in cancer in Europe
- Provide evidence to inform health policies, clinicians and citizens as well
- monitoring variations in cancer survival by country, region, age, time and sex
- updating cancer prevalence
- updating epidemiologic indicators for rare cancers

New aims for EUROCARE-6 (in addition to those included in EUROCARE-5):

- Increase the use of morphology to analyse clinically relevant cancer entities
- Extend the use of stage (a higher completeness/quality is expected)

Data Sets

- all invasive, primary, malignant tumours, except non-melanoma skin
- *in situ* tumours of breast, cervix, colon-rectum and skin melanoma
- non malignant tumours of central nervous system and urinary bladder
- multiple tumours, DCO, cases discovered at autopsy

EUROCARE usually asks an update of the complete dataset for each registry so as to perform trend analysis and long-term survival analysis

Study period
Past EUROCARE (and also CONCORD) experience shows that there is an average lag time of three years between last incidence data available and year of the call. EUROCARE-6 will ask all index tumours diagnosed up to 2012 with vital status updated to 31/12/2013

Variables
The variable list discussed at ENCR-JRC meetings is considered. However, the following decisions were taken by the EUROCARE SC:

- Distinction between CORE (specify that these are the required variables for EUROCARE) and ADDITIONAL, rather than compulsory and non compulsory variables
- Ask CRs for full dates of diagnosis and vital status as CORE variables. IF (and only if) day cannot be provided - due to confidentiality issues- → ask for computing duration in days (rephrase footnote page 5 *** as in CONCORD)
- Add Ann Arbor stage for NHL, Gleason for prostate, Breslow for skin melanoma
- Add 5th edition of TNM (not only 6 and 7)
- FIGO stage: give the possibility to provide format details: specify 1a, 1.a.1, 1.a.2, 1b rather 1 this should be verified also for other stage classification (Duke,…)
- Specify that the sentinel nodes have to be included in the number of examined nodes
- The period of reference for stage or other new variables maybe limited to the most recent years of diagnosis (e.g., for stage, data quality is relatively good starting from 2000 or 2001)
- C/factor Must better investigate variable availability in EUROCARE5 DB, to decide whether to mantain the variable in EUROCARE 6 if poor quality or high level of missing values we evaluate the possibily to drop it from the variable list
- Include value **8=not applicable** for each variable (exe sentinel node), in addition to 9=missing
- Inclusion of STAGE in the CORE variables for EUROCARE, because stage is key to discussion of 'over-diagnosis', to assess how oncologists today are able to improve survival of patients with advanced stage, and whether targeted therapies are able to improve survival of advanced cases. Data comparability is an open issue. Collecting additional information on stage definition/classification is relevant. The benchmarking experience (ICBP) suggests that even data from a few cancer registries can be very useful
- rural/urban differentiation at individual level may be included as additional variable after verifying the existence of a common standard definition in Europe and the availability of this kind of data in the CR (see Eurostat, CIVC)

Format
The EUROCARE SC suggested to

- revise variable format to comply with best IT standards, eg comma or special character separators,
- INT rather than FLOAT or ALPHANUMERIC (a specific doc on this will accompany the EUROCARE protocol)

The inclusion in the EUROCARE protocol of the above contents (Timeline, Variables and Formats) will be discussed with the ENCR "portal and data call" working group.

Methods

Alignment of methods and softwares between Eurocare and CONCORD was discussed. Pohar-Perme is recognised as best unbiased estimator of net survival, although age-adjusted relative survival estimates (Ederer 2) are very close and robust as well. In general, the possibility to use net survival rather than relative survival is considered preferable.

Time plan

According to the decisions taken during the EUROCARE and ENCR-JRC Meeting of Dec 12th, 2014, in Milan, ENCR and EUROCARE will both define their protocols by February. JRC will develop the ENCR-JRC portal for data submission by the end of March 2015.

During the month of February, the "ENCR portal and data call working group" will discuss the ENCR call and the requirements proposed by the different stakeholders (i.e., ENCR, EUROCARE, CONCORD), and on March 10th a larger meeting with the stakeholders is organised at JRC-Ispra for a final agreement on the Joint protocol, call management, and timeline.

An ENCR-JRC protocol including EUROCARE-6 variables for survival and prevalence analysis will be circulated by JRC to the ENCR registries by the end of March. Registries wishing to participate in the EUROCARE-6 study will provide a signed consent during the data submission process. A protocol for quality checks will be based on existing protocols and the document agreed during the quality checks organised by the ENCR-JRC working group.

Call management and checks

A suitable process to accommodate time lag and the contractual and funding constraints of EUROCARE-6 is here described:

1. Data submission via the JRC portal (only possible if data files respect the data call protocol format);
2. A first quick check is done by JRC and only whether the format is acceptable and whether valid values are delivered, the data flagged for participation in EUROCARE is transmitted to EUROCARE;
3. Data cleaning by the EUROCARE team, using the current EUROCARE Quality Checks software;
4. EUROCARE will ask registries to check and fix errors flagged by the checks through the ENCR-JRC portal. An automatic message will be sent to the registry that the data checks are ready. The JRC will coordinate this process with the EUROCARE-6 group assistance;
5. Registries' resubmission of corrected data to the JRC-ENCR portal with transmission to EUROCARE as in step 2.

Should the deadline for the call not be viable, EUROCARE-6 call will be launched by April 30 (through ISS portal) with automated transmission to JRC.

Funding

The coordinating centre had the confidence to perform EUROCARE-6 in the similar time followed in EUROCARE-5 as the initial financing conditions are similar (financing is lower but in Rome some researchers/technicians obtained permanent position in the last three years).

G. Gatta
Updates from RareCareNet
The RARECAREnet experience now at its second round was illustrated especially with reference to the use of morphology in the definition of clinical entities. About the most recent experience we performed hospital volume analyses to know how rare cancer are centralised in a country. In this framework, we discussed the inclusion of hospital information for diagnosis and treatment at individual level as an additional variable in the EUROCARE 6 call. The conclusion was that it is difficult, as clinicians and hospital owners are very defensive with respect to the publication of this kind of information**.** However, the use of this information in an aggregate way as proposed by RARECAREnet is very useful and important from the public health point of view.

M. Coleman
Updates from CONCORD
The state of the art of the CONCORD study was illustrated.

S. Francisci
Updates on the EUROCARE-5 Monograph on EJC
The following timetable was agreed with first authors of the 13 articles included in the European Journal of Cancer (EJC) monograph:

October 17th, 2014 → 1st draft circulated to co-authors
October 31st, 2014→ 2nd draft circulated to EUROCARE WG members
January 15th , 2015→ comments from EUROCARE WG members
February 15th, 2015 → comments from the Monograph Guest Editors (Renee Otter, Maja Primic Zakeli, Silvia Francisci, and Pamela Minicozzi)
March, 2015 → final submission to EJC

The state of the art of paper circulation among co-authors and/or WG members on 29 January 2015 was the following:

	Title	**First Author**	**State of the Art**
1	Database and Methods	Silvia Rossi	Sent to co-authors
2	All cancers combined	Paolo Baili	Sent to WG
3	Head & Neck, larynx	Gemma Gatta	Sent to WG
4	Upper Gastro-Intestinat tract: Oesophagus, stomach, small intestine	Lesley Anderson	Sent to WG
5	Lower Gastro-Intestinat tract: colorectum, anal canal, anus	Bernd Holleczek	Sent to WG
6	Liver, biliary tract, pancreas	Jean Faivre	Sent to co-authors
7	Skin Melanoma	Emanuele Crocetti	Sent to WG
8	Breast, female genital	Milena Sant	Sent to WG
9	Male genital	Sent to WG	Sent to WG
10	Urologic: kidney, urether, urinary bladder	Rafael Marcos-Gragera	Sent to WG
11	Brain, CNS	Otto Visser	Sent to co-authors
12	Lung, Pleura	Silvia Francisci	Sent to co-authors
13	Haematological malignancies	Roberta De Angelis	Sent to co-authors

NOTE: Discussion on warnings is still pending!

Discussion on EUROCARE and ENCR Steering Committee (SC) Representations

Alexander Katalinic makes himself available for liaising ENCR and EUROCARE activities given his presence in both SC committees, and will ask the ENCR SC the possibility for representatives of the EUROCARE to be invited in specific ENCR SC Meetings, where relevant

Conclusions

- Mid February: The EUROCARE protocol with the ENCR feedback is circulated to the EUROCARE Steering Committee Members
- 28th February 2015: Deadline for SC comments
- March 10th: ENCR-JRC Meeting with Stakeholders at JRC, Ispra
- Report on the ENCR-JRC Meeting with Stakeholders circulated to EUROCARE SC Members