

ENCR-JRC Call for Data, 2015:

Registry questionnaire

April 2015

Contact information

Please enter the name of your registry:

Please enter your name:

Please enter your email address:

1. Cancer case file

1.1 Please state what period of time is covered in this data submission call?

From to

1.2. Please indicate the type of the registry:

- Population-based
- Hospital-based
- Other. Please specify:

1.3 Please indicate the registry coverage:

- National
- Regional

Note: Regional coverage refers to non-national coverage, for example: region, province, city, etc.

1.4 Please name the area covered by the registry (for example: Sweden, Turin city, etc.):

1.5 Please state the size of the population covered by the registry:

Number of inhabitants:

Year of reference:

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1.6 The cancer registry collects information on:

- All ages
- 0-14 year olds
- 0-19 year olds
- Other age range. Please specify:

1.7 The cancer registry collects information on:

- All tumours
- Specific topographies and/or morphologies. Please specify:

1.8 Are cancer registry data linked to death certificates?

- Yes, for all causes of death
- Yes, but only when the cause of death is cancer
- No. Please specify (for example, not permitted under data protection legislation)

1.9 Does your registry record non-melanoma skin cancer?

- Yes
- No

If **yes**,

1.9.1 Do you consider that the registry has "close- to- complete" data about non-melanoma skin cancer?

- Yes
- No

Do you have any additional comments?

1.10 Does the registry record in-situ tumours?

- No
- Yes, all topographies
- Yes, but only for selected topographies. Please specify:

Do you have any additional comments?

1.11 Does the registry record uncertain/borderline behaviour tumours?

- No
- Yes, all topographies
- Yes, but only selected topographies. Please specify:

Do you have any additional comments?

1.12 Does the registry record benign tumours?

- No
- Yes, all topographies
- Yes, but only selected topographies. Please specify:

Do you have any additional comments?

1.13 Does the registry provide information on FULL date of birth?

- Yes
- No. Please specify:

1.14 Do you impute the incomplete date of birth?

- No
- Yes, the day of birth for all cases
- Yes, the day of birth for some cases when day is not available
- Yes, the month of birth for all cases
- Yes, the month of birth for some cases when month is not available

If **yes**, please describe the imputation procedure:

1.15 Does the registry provide information on FULL date of incidence?

- Yes
- No. Please specify:

1.16 Do you impute the incomplete date of incidence?

- No
- Yes, the day of incidence for all cases
- Yes, the day of incidence for some cases when day is not available
- Yes, the month of incidence for all cases
- Yes, the month of incidence for some cases when month is not available

If **yes**, please describe the imputation procedure:

1.17 Does the registry provide information on FULL date of the last known vital status?

- Yes
- No. Please specify:

1.18 Do you impute the incomplete date of the last known vital status?

- No
- Yes, the day of last known vital status for all cases
- Yes, for some cases the day of last known vital status is imputed, when day is not available
- Yes, the month of of last known vital status for all cases
- Yes, for some cases the month of of last known vital status, when month is not available

If **yes**, please describe the imputation procedure:

1.19 Does the registry follow-up patients to assess their vital status?

- Yes, for all cases
- Yes, for selected cases. Please specify:

- No, not at all

If **yes**,

1.19.1 Which method of follow-up is used?

- Active follow-up (information obtained by contacting hospitals, clinicians, etc)
- Passive follow-up (linkage of registry records with death notifications or other information sources)
- Mixed follow-up. Please specify approximately what % of cases have active follow-up

Please specify the information sources:

1.19.2 How often is the vital status of the patient checked? (e.g. set times, for example every six months/ every year - for all patients, or every 5 years, for groups of patients with diagnosis in the previous 5 years). Please specify:

1.19.3 In case of passive follow-up, please specify how the date of last known vital status is checked:

1.20 Does the registry collect information on stage?

- No
 Yes

If **yes**,

1.20.1 The sources of data on stage are:

- Clinical records
 Pathological records
 Other (e.g. hospital admission records)

1.20.2 Please, specify the information on stage that the registry routinely collects:

- Pathological TNM
 Clinical TNM
 TNM not specified if pathological or clinical
 TNM stage grouping
 Condensed TNM
 Summary extent of disease
 Dukes' stage
 FIGO stage
 Ann Arbor staging
 Gleason grading system for prostate cancer
 Breslow for melanoma staging
 Others. Please, specify:

Do you have any additional comments concerning stage?

1.21 Do you record information about treatment in the registry?

Yes

No

If **yes**,

1.21.1 Please, provide a description of the variables, if they are different than those in the protocol:

1.21.2 Please specify the sources of data on treatment:

1.22 For this submitted dataset, did you use any software for data checks?

Yes

No

If **yes**,

1.22.1 Which software have you used for this call?

IARCcrgTools

Others. Please specify:

1.23 Have you used any software for data conversion (topography/morphology) for this data call?

- No
- Yes for topography
- Yes for morphology

If **yes**,

1.23.1 Which software did you use?

- IARCcrgTools
- Others. Please specify:

1.23.2 Please specify which version of ICDO was **originally** used to code tumour morphology in your dataset over time:

ICDO-1: From to

ICDO-2: From to

ICDO-3: From to

2. Population data

2.1 Please document any format or coding if different than recommended:

2.2 Please specify the population data sources:

2.3 Please specify the reference date for the data submitted:

- January 1
- June 30
- December 31
- Other. Please specify:

3. Mortality data

3.1 Please document any format or coding if different than recommended:

3.2 Please list the mortality data sources:

4. Life tables

4.1 Please specify the life table data sources:

4.2 The life table data contain:

- Death rates
- Death probabilities