ENCR
European Network
of Cancer Registries

Call for Data protocol for European population-based cancer registries

Organised by the European Commission's Joint Research Centre (JRC) and the European Network of Cancer Registries (ENCR)

in **collaboration** with
the International Agency for Research on Cancer (IARC) and
EUROCARE

Projects served by the data call:

- European Cancer Information System (ECIS)
- Cancer Incidence in Five Continents (CI5-XII)
- EUROCARE-7

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1. INTRODUCTION

The Joint Research Centre (JRC) is one of the Directorate Generals of the European Commission that serves as a key partner to many of the Commission's services in its technical and scientific capacity. In this role, the JRC is working closely with the ENCR Steering Committee to agree the priorities for enhancing the value and utilisation of cancer data at European Union (EU) level.

The European Network of Cancer Registries (ENCR) was established in 1989, within the framework of the Europe Against Cancer Programme of the European Commission. The ENCR is a professional, non-profit society dedicated to promoting collaboration between cancer registries (CRs), defining data collection standards and providing training for CR personnel. It aims to strengthen the basis for monitoring cancer burden in the EU and the rest of Europe, through the provision of regular and timely information from European CRs.

Since 2012 the JRC hosts the ENCR secretariat and supports ENCR activities aimed at standardisation and harmonisation of cancer data across Europe. Moreover, the following priorities have been identified and pursued:

1. The availability of accurate, reliable, comparable and up-to-date cancer indicators (incidence, mortality, survival, prevalence) across Europe;
2. The development and maintenance of the European Cancer Information System (ECIS) as a comprehensive cancer-information resource for hosting and processing the European cancer data.

ECIS is a comprehensive health and research infrastructure harmonising CRs' data, producing and disseminating cancer burden indicators to assess and facilitate the interpretation of the dynamics of cancer in Europe. A key component of the system is the ECIS web application, launched in February 2018 and populated with indicators from around 34 million records submitted by approximately 150 ENCR-affiliated registries from 34 European countries.

To update the indicators in ECIS, the ENCR Secretariat at JRC coordinates calls to the CRs that might serve different initiatives on CR data (among which IARC's Cancer Incidence in Five Continents (CI5), the EUROCARE study and possibly others by forwarding pre-cleaned data to the respective studies. Prior to forwarding data to other organisations or to making

aggregated data publically available, the JRC validates the data according to pre-defined protocols. Once cleaned, aggregated data is uploaded into the ECIS web application.

The present document details the guidelines for the data submission to the JRC, providing detailed instructions on the content and process of the submission through the fully automated and secured JRC-ENCR portal. Submitted datasets will be processed by the Cancer Information team at the JRC - to check for compliance with ENCR agreed standards, and will be analysed and stored on secure servers in order to ensure confidentiality.

For registries having agreed to participate also in IARC's CI5 – Volume XII (CI5-XII) project, after validation and standardisation, the JRC will forward relevant datasets to IARC. Related specificities for the CI5-XII call will be highlighted throughout the document.

The present protocol details also the specifications for the EUROCARE 7 call.

To facilitate the submission and improve the quality of CRs data, the ENCR-JRC recommend to check beforehand the format of required files and the internal consistency of the incidence data using the JRC-ENCR Quality Check Software (QCS), latest version (1.8.1) available and freely downloadable here. The checks performed by the JRC-ENCR QCS are based on the JRC Technical report "A proposal on cancer data quality checks: one common procedure for European cancer registries".

2. Timeline for data submission

Data submitted by CRs will be used to update annually the historical data available online in the ECIS web application, as well as to compute predictions for cancer incidence and mortality. The annual deadline for submission to the ECIS project is DD/MM of each year.

CI5-XII specifications: DD/MM is the deadline for the submission.

EUROCARE specifications: For the EUROCARE-7 project incidence data until 2017 with complete follow-up until at least 31/12/2018 will be considered.

3. REQUIRED DATA FILES

The following files should be submitted:

3.1 Cancer incidence file

3.2 Population file

3.3 Mortality file

3.4 Life tables

3.5 Questionnaire

3.1. Cancer incidence file

The cancer incidence file to be submitted shall include only pseudonymised data. The process of pseudonymisation is responsibility of the registries, and must be carried out at the registry level prior to submission of the incidence file.

Inclusion criteria for reportable incident cases:

3.1.1. Time period

All available registration years which are considered complete should be submitted to update the **ECIS Database**.

CI5-XII specifications: The target incidence period is 2013-2017. Data from three consecutive years within this time period are the minimum that will be considered for publication. CRs are, however, encouraged to submit all available data from years prior to 2013.

EUROCARE specifications: All available incidence data until 2017 with vital status updated not earlier than 31/12/2018.

3.1.2. Reporting cases

- All primary malignant tumours (ICD-O behaviour=3), including squamous cell carcinomas of skin.
- In situ tumours (behaviour=2): breast (ICD-O C50), Urothelial tumours (C65-C68), Ovary (C56), and skin melanoma.
- Uncertain behaviour tumours (behaviour=1): Urothelial tumours (C65-C68), Ovary (C56), central nervous system (C70-C72, C751-C753) and gastrointestinal stromal tumours (GIST) (8936/1).
- Benign tumours (behaviour=0): Central nervous system (C70-C72, C751-C753) and gastrointestinal stromal tumours (GIST) (8936/0).

3.1.3. Multiple primary tumours

All multiple primary tumours (MPT) are to be retained in the file. Due to differences on MPT definition among the European CRs, it is recommended to submit all primary tumours included in the CR dataset to assure data comparability.

3.1.4. Age

- All ages are eligible in the data submission.
- In age-restricted CRs, such as childhood CRs, all subsequent primary tumours of the registered patients should be included, if available, irrespective of age at diagnosis.

3.1.5. File format

The file should be formatted as follows:

- One record per tumour.
- The file should be a text file (.csv or .txt) with **semi colon (;) separators** and should include a header, with variables' names and order as specified in the text below.

  PAT; MoB; YoB; Age; Sex; Geo_Code; Geo_Label; TUM; MoI; YoI; BoD; Topo; Morpho; Beh; Grade; Autopsy; Vit_stat; MoF; YoF; Surv_time; ICD; CoD; TNM_ed; cT; cN; cM; pT; pN; pM; ToS; Stage; Surgery; Rt; Cht ; Tt; It; Ht; Ot; SCT
- Variables must be submitted, for all records, according to the codes detailed in Table 1.

3.1.6. Data quality

Data should be verified and corrected before submission using the latest version of the JRC-ENCR Quality Check Software (QCS) downloadable from the ENCR website (https://www.encr.eu/download)[1].

3.1.7. Requested variables and coding

The name, description and format, with corresponding missing/unknown values and coding schema, are summarised in Table 1.

Variables related to the patient

- Patient identification code (PAT)

  Alphanumeric variable, maximum fifty characters.

  Definition: The patient identification is a unique code assigned by the registry, or generated at the time of data submission, to refer to each registered cancer patient. For data protection reasons, it

should not be the official personal identification number and should not to be used elsewhere (e.g. in a hospital).

Should you need, pseudonymisation scripts in Stata, SAS or R are made available by the JRC.

Coding: Missing values are not allowed.

This code will be used for identifying patients with more than one primary tumour and for sending queries and logs to the CRs during the data cleaning process.

CRs need to keep a record of the correspondence between the patient identification number used in the registry and the code provided in their data submission.

- Date of birth

It consists of two separate variables: month and year of birth. The **date of birth will be used to compute/check the age at diagnosis**, therefore after validation of the dataset the two variables will be deleted from the final dataset, as they will be no longer needed.

- Month of birth (MoB)

  Numeric variable, maximum two digits.

  Definition: Month of birth of the patient.

  Coding: The range of valid values is 1-12. **If the month of birth cannot be provided** for some reasons, it should be **coded as 99**.

  It is preferable to have the data without imputation of the missing values (value=99). If, however, the month of birth for some tumours has already been imputed, please detail the imputation rule in the data call questionnaire (question 1.13).

- Year of birth (YoB)

  Numeric variable, four digits.

  Definition: Year of birth of the patient.

  Coding: Provide the full 4-digit year (for example 1942). The year of birth should not be less than 1842 (>1842). If the year of birth cannot be provided, it should be coded as 9999.

- Sex at birth (Sex)

Numeric variable, one digit.

Definition: This variable refers to the biological and physiological characteristics that define men and women.

Coding: It should be coded as 1 (male), 2 (female) or 3 (other). If sex cannot be provided, it should be coded as 9.

Tumour variables

- Code of the geographical area of residence at diagnosis (Geo_code)

Alphanumeric variable, max 10 digits.

Definition: Code for the geographical area of residence of the patient at the time of diagnosis for each tumour.

For harmonisation purposes, the Geo_code should follow the NUTS (Nomenclature of Territorial Units for Statistics) classification level 2 (NUTS2).

NUTS codes are the geolocation variables used by EUROSTAT in all their data sets, subdividing the economic territory of the European Union (EU) into regions at three different levels (NUTS 1, 2 and 3 respectively, moving from larger to smaller territorial units). NUTS geolocation codes are available for all EU-27 countries plus UK, as well as countries belonging to the European Free Trade Association (EFTA), candidate countries awaiting accession to the EU or potential candidates.

The NUTS codes will be available for each cancer registry in the JRC portal. More information can be found in Annex 1.

For other European countries where the NUTS classification is not available, the Geo_code variable corresponds to the highest level of administrative sub-divison in the area covered by the cancer registry which can be provided.

If a valid value cannot be provided for some cases, it should be coded as XX99.

If it is not applicable, it should be left blank.

Note: Due to the peculiarity of French site-specific CRs, whose area overlaps with the area of general registries, the CRs of France are requested to code the geographical area according to the NUTS3-***Départements.***

- Name of the geographical area of residence at diagnosis (Geo_label)

Alphanumeric variable, max 50 digits.

Definition: Description (name) for the geographical area of residence of the patient at the time of diagnosis for each tumour.

The Geo_label is the name of the geographical area corresponding to the Geo_code.

If a valid description cannot be provided for some cases, it should be coded as 9.

If it not applicable, it should be left blank.

- Tumour identification (TUM)

Alphanumeric variable, maximum fifty characters.

Definition: This variable is assigned by the registry. It allows the identification of two or more tumours for the same patient. It can be (but does not need to) a sequence number.

For data protection reasons, it should not be the official personal identification number and should not be used elsewhere.

Should you need, a pseudonymisation scripts in Stata, SAS or R are made available by the JRC. Please refer to the "Submission instructions" in section 4 of this document for additional details.

Coding: Missing values are not allowed.

The combination of the patient identification variable and the tumour identification variable should be unique for each tumour.

- Age at diagnosis (Age)

Numeric variable, maximum three digits.

The exact age is important because it is used to calculate age-specific and age-standardised rates. If available, cancer registries should use **day**, **month** and **year** of the date of birth and the date of incidence to calculate the exact age at diagnosis for each tumour.

Definition: **Latest completed year of age** at the time of diagnosis.

Coding: The range of valid values is 0-120.

- Date of incidence

It consists of two separate variables: month and year of incidence.

The updated ENCR recommendation (https://encr.eu/sites/default/files/pdf/incideng.pdf)[2] should be followed to record the date of incidence.

- Month of incidence (MoI)

Numeric variable, maximum two digits.

Definition: Month of incidence recoded according to the ENCR recommendations[2].

Coding: The range of valid values is 1-12. **If the month of incidence cannot be provided** for some reasons, it should be **coded as 99**.

It is be preferable to have the data without imputation of the missing values. If, however, the month of incidence for some tumours has already been imputed, please detail the imputation rule in the data call questionnaire (questions 1.15).

- Year of incidence (YoI)

Numeric variable, four digits.

Definition: Year of incidence recorded according to the ENCR recommendations[2].

Coding: Missing values are not allowed. The range of valid values is from 1941 to present.

- Basis of diagnosis (BoD)

Numeric variable, one digit.

Definition: This variable indicates the degree of certainty with which the diagnosis of cancer has been established. This information will be used for computing quality indicators, such as the percentage of cancer cases identified through the Death Certificate Only (DCO), or the percentage of cases with histological verification of the diagnosis.

Coding: This variable should be coded, according to the ENCR recommendations (https://encr.eu/sites/default/files/pdf/basisd.pdf)[3]:

0 → Death certificate only (DCO)

1 → Clinical

2 → Clinical investigation

4 → Specific tumour markers

5 → Cytology

6 → Histology of a metastasis

7 → Histology of a primary tumour

9 → Unknown

Note: Cases registered as DCO are cancers for which no information could be obtained, other than a death certificate mentioning cancer. These cases are included in cancer incidence statistics for the year of death. Nevertheless, the true date of diagnosis and the duration of the survival are unknown, and these data cannot normally be included in survival analyses.

- Topography (Topo)

Alphanumeric variable, four characters.

Definition: This variable indicates the anatomic site of the primary tumours.

Coding: It should be coded according to the third revision of the International Classification of Diseases for Oncology (ICD-O-3)[4].

CRs who use other International Classifications of Diseases (ICD) versions should convert their codes to ICD-O-3 prior to submission, using any appropriate software (for instance, the IARCcrgTools).

The full four-digit characters' ICD-O-3 code should be provided, including the initial letter, but without the decimal point (“.”). For example, supraglottis should be coded as C321.

When the primary site of the tumour is unknown, the topography should be coded as C809. The topography of the metastasis should not be attributed to the primary tumour.

- Morphology (Morpho)

Numeric variable, four digits.

Definition: This variable records the type of cell that has become neoplastic, the specific histological term.

Coding: It should be coded according to any version of the ICD-O-3 (ICD-O-3.1 or ICD-O-3.2)[4,5]. CRs who use other ICD versions should convert their codes to ICD-O-3 prior to submission, using any appropriate software (for instance, the IARCcrgTools).

The valid range of morphology codes is 8000-9993. Missing values are not allowed. **Malignant tumour, NOS, should be coded as 8000, leukaemia, NOS should be coded as 9800 and malignant lymphoma, NOS as 9590 (with behaviour code 3, see below).**

- Behaviour (Beh)

Numeric variable, one digit.

Definition: This variable indicates whether a tumour is malignant, benign, in situ, or of uncertain behaviour.

Coding: It should be coded according to any version of the ICD-O-3 (ICD-O-3.1 or ICD-O-3.2)[4,5] as follows:

0 → Benign neoplasms

1 → Neoplasms of uncertain or unknown behaviour

2 → In situ neoplasms

3 → Malignant neoplasms stated or presumed to be primary

Note: codes 6 (malignant, metastatic site/malignant, secondary site) and 9 (malignant, uncertain whether primary or metastatic site) should not be used by CRs; the correct behaviour code in these case is 3.

- Grade (Grade)

Numeric variable, one digit.

Definition: This variable describes how much a tumour resembles the normal tissues from which it arose and is also used to denote cell lineage for leukaemias and lymphomas.

Coding: Except for tumours of the central nervous system and urothelial tumours, **solid malignant tumour** should be coded according to the ICD-O-3[4] as follows:

1 → Well differentiated

2 → Moderately differentiated

3 → Poorly differentiated

4 → Undifferentiated, anaplastic

When a diagnosis indicates two different degrees of grading or differentiation, the higher number should be used as the grade code. For example: if the diagnosis is moderately differentiated squamous cell carcinoma with poorly differentiated areas, the grade should be coded as 3.

For **leukaemias and lymphomas**:

5 → T-cell; T-precursor

6 → B-cell; Pre-B; B-precursor

7 → Null cell; Non T-non B

8 → NK cell (natural killer cell)

For **all**:

9 →Unknown

The grade of the central nervous system tumours should be coded according to table 27 of the ICD-O-3 (pages 28 and 29)[4].

Variables related to the follow-up

- Incidental finding of cancer at autopsy (Autopsy)

Numeric variable, one digit.

Definition: It marks the cases discovered only at autopsy, that are included in cancer incidence statistics. For these cases, the date of incidence is the same as the date of death. This variable is extremely important in survival analysis because cases incidentally discovered at autopsy, as well as DCO cases, must be excluded from survival statistics.

Coding: It should be coded as:

0 → No (not found at autopsy)

1 → Yes (found at autopsy)

9 → Unknown

Note: For the cases discovered only at autopsy the vital status is always 2 (dead) and the survival time is 0 days.

- Last known vital status (Vit_sta)

Numeric variable, one digit.

Definition: This variable describes the patient's vital status as last known to the CR. This information may be collected using either 'active' or 'passive' methods of follow up.

Coding: It should be coded as:

1 → Alive

2 → Dead

9 → Unknown

If the CR adopts a passive follow-up, patients who are not known to be deceased would normally be assumed to be alive at the date of the most recent linkage between the registry data and a death index or other vital status records. The vital status of those patients should be coded as "1" (alive).

If patients cannot be traced by any active follow-up procedure, their vital status may remain undetermined and should then be coded as "9" (unknown).

- Date of last known vital status

This variable consists of two separate variables: month and year of last known vital status.

It corresponds to the most recent date for which the patient's last known vital status was available.

If the patient is deceased, the date of last known vital status should be the date of death.

For registries using passive follow-up and the patient is alive, it corresponds to the most recent date for which death certificates have been linked to registrations.

If the patient has emigrated or has been lost to follow-up, the last date at which he/she was known to be alive should be reported.

The date of last known vital status will be used to compute/check the duration of survival, therefore after validation of the dataset the two variables month and year of last known vital status will be deleted from the final dataset, as no longer needed.

- Month of last known vital status (MoF)

  Numeric variable, maximum two digits.

  Definition: The month of the most recent date for which the patient's last known vital status was available.

  Coding: The range of valid values is 1-12. When the month of the last known vital status **cannot be provided**, it should be coded as 99.

  It is preferable to have the data without imputation of the missing values. If, however, the month of the last known vital status for some tumours has already been imputed, detail the imputation rule in the data call questionnaire (questions 1.20.2).

- Year of the last known vital status (YoF)

  Numeric variable, four digits.

Definition: Year of the most recent date for which the patient's last known vital status was available.

Coding: The range of valid values is from 1941 to present.

When the year of the last known vital status cannot be provided, it should be coded as 9999.

EUROCARE project: 31/12/2018 is the common date to be considered for follow-up.

- Duration of survival in days (Surv_time)

Numeric variable, maximum five digits.

The exact duration of survival is essential. The CRs should use day, month and year of the date of incidence and the date of last known vital status to calculate the duration of the survival in days.

Definition: It is the number of days between full dates (including days) of the last known vital status and the date of incidence.

Coding: The values should be ≥ 0. When the duration of survival cannot be provided, it should be coded as 99999.

- Official underlying cause of death (CoD)

Alphanumeric variable, maximum four characters.

Definition: This variable is used to estimate cause-specific survival. It records the official underlying cause of death according to standard international coding rules.

Coding: It should be coded according to the International Classification of Diseases (ICD). The dot (.) between the third and the fourth digits should not be included. For example, if the underlying cause of death is malignant neoplasm of laryngeal cartilage, this should be coded as C323 (according to ICD-10)[7]. If the underlying cause of death is acute myocardial infarction unspecified, the CoD should be coded as 4109 (according to ICD-9)[8].

When this variable is not applicable, it should be left blank.

Note: If vital status is 1 (alive) the CoD and ICD should be left blank; if vital status is 2 (dead) and the cause of death is unknown, CoD should be coded as R99 (ICD-10)/7999 (ICD-9) or 9999 if ICD is different from ICD-9 or ICD-10.

- ICD edition used for coding cause of death (ICD)

Numeric variable, maximum two digits.

Coding: This variable, coded as a number lower than 12, should be provided if the underlying cause of death has been reported.

When this variable is not applicable, it should be left blank.

Note: if vital status is 2 (dead) and ICD is unknown, it should be coded as 99.

Variables related to the tumour stage at diagnosis

The stage at diagnosis is particularly useful information for the interpretation of international survival comparisons, for the evaluation of screening programs, and other studies.

Notes:

- When TNM and/or TNM stage grouping is/are available, they should be reported in preference to any other coding system.
- If cTNM (clinical TNM) is available and the primary tumour was not resected, the pTNM (pT, pN, pM) should be left blank.
- If the CR does not know whether the TNM is pathological or clinical, it should be recorded as clinical and be specified in the data call questionnaire.
- If TNM is not available or not applicable, cTNM and pTNM should be left blank and (if possible) type of stage (stage system) and stage should be reported.

- TNM edition (TNM_ed)

  Numeric variable, maximum two digits.

  This variable should be provided when any TNM and /or TNM stage grouping have being reported.

  Coding: Valid values are numbers ≤ 8, or 99 when the information is not available.

- TNM: clinical primary site T (cT)

  Alphanumeric variable, maximum twelve characters.

  Definition: The variable encodes information on the extent of the primary tumour, based on clinical evidence.

  Coding: It should be coded according to any edition of the TNM classification without the "T" - for example: 1a, not T1a. When the information cannot be provided, it should be coded as 9. Since TNM ed. 7, MX (distant metases cannot be assessed) is no longer a valid option.

- TNM: clinical lymph nodes N (cN)

  Alphanumeric variable, maximum twelve characters.

  Definition: This variable provides information on the absence or presence and extent of the regional lymph node metastasis, based on clinical evidence.

  Coding: It should be coded according to any edition of the TNM classification, without the "N" - for example: 0, not N0; 3a, not N3a. When the information cannot be provided, it should be coded as 9.

- TNM: clinical metastases M (cM)

Alphanumeric variable, maximum ten characters.

Definition: This variable describes the absence or presence of distant metastasis, based on clinical evidence.

Coding: It should be coded according to any edition of the TNM classification, without the “M" - for example: 0, not M0; 1a, not M1a. When the information cannot be provided, it should be coded as 9.

- TNM: pathological primary site T (pT)

Alphanumeric variable, maximum twelve characters.

Definition: This variable encodes information on the extent of the primary tumour based on pathological evidence.

Coding: It should be coded according to any edition of the TNM classification, without the “T” - for example: 1a, not T1a.

When the information cannot be provided, it should be coded as 9.

- TNM stage, pathological lymph nodes N (pN)

Alphanumeric variable, maximum twelve characters.

Definition: This variable provides information on the absence or presence and extent of regional lymph node metastasis, based on pathological evidence.

Coding: It should be coded according to any edition of the TNM classification, without the “N”- for example: 0, not N0; 3a, not N3a. When the information cannot be provided, it should be coded as 9.

- TNM stage, pathological metastases M (pM)

Alphanumeric variable, maximum twelve characters.

Definition: This variable describes the absence or presence of distant metastasis, based on pathological evidence.

Coding: It should be coded according to any edition of the TNM classification without the “M” - for example 1a, not M1a. When the information cannot be provide, it should be coded as 9.

- Staging system (ToS)

Alphanumeric variable, maximum three characters.

Definition: This variable describes the system used by the CR for coding stage.

Coding: It should be coded according to the following categories (Table 1):

A → Ann Arbor/ Lugano stage

D → Dukes' stage

E → Summary extent of disease

F → FIGO stage

S → TNM stage, unknown whether clinical or pathological

clS → clinical TNM stage

paS →pathological TNM stage

cpS → combination of clinical & pathological TNM stage

coS → condensed TNM stage

esS → essential TNM stage

T1 → Toronto Tier 1 stage for paediatric tumours

T2 → Toronto Tier 2 stage for paediatric tumours

8 → Other system

When the information cannot be provided, it should be coded as 9.

- Stage (Stage)

Numeric variable, one digit.

Definition: This variable is defining the extent of disease at diagnosis.

When a CR reports TNM they should not submit stage, which stage will be coded centrally

Coding: it should be coded according to the following categories (Table 1):

0 → Stage 0, stage 0a, stage 0is, carcinoma in situ, non-invasive

1 → Stage I, FIGO I, localized, localized limited (L), limited, Dukes A

2 → Stage II, FIGO II, localized advanced (A), locally advanced, advanced, direct extension, Dukes B

3 → Stage III, FIGO III, regional (with or without direct extension), R+, N+, Dukes C

4 → Stage IV, FIGO IV, metastatic, distant, M+, Dukes D

When the information cannot be provided, it should be coded as 9.

Variables related to treatment

Treatment variables refer to the curative **first course of anticancer therapy after diagnosis**. Purely symptomatic therapy (e.g. bypass surgery, pain relief) should not be considered.

- Surgery (Surgery)

Numeric variable, one digit.

Coding: It should be coded according to the following categories (Table 1):

0→ No

1 → Yes, without specification

2 → Yes, local surgery only

The following procedures should be considered as local surgery: polypectomy (mainly gastro-intestinal tract), transurethral resection (TUR; bladder & other urinary tract), cone biopsy/loop excision (cervix), as well as all other procedures which leave the organ in situ, such as cryosurgery, laser coagulation, thermoablation, radiofrequency ablation (RFA), etc.

3 → Yes, 'operative' surgery

'Operative' surgery includes all resections of the tumour which require the removal of an organ or a part of that organ, such as a lobectomy, hemicolectomy, hysterectomy, cystectomy, prostatectomy, etc.

9 → Missing/Unknown

Notes:

- If available, type of surgery (*local surgery* versus *operative surgery*) should be recorded for solid cancers of the following topographies: C01-C06, C16-C20, C30-C34, C53-C55, C61 and C65-C68. For other tumours, code 1 (surgery without specification) suffices.
- If both *local surgery* and *operative surgery* were performed for the same tumour, *operative surgery* should be registered.

- Radiotherapy (Rt)

Numeric variable, one digit.

Coding: It should be coded according to followingaccording to the following categories (Table 1):

0 → No

1 → Yes, without other specification

2 → Yes, neoadjuvant (pre-operative) radiotherapy

3 → Yes, adjuvant (post-operative) radiotherapy

9 → Unknown/missing

- Chemotherapy (Cht)

Numeric variable, one digit.

Coding: It should be coded according to the following categories (Table 1):

0 → No

1 → Yes, without other specification

2 → Yes, neoadjuvant (pre-operative) chemotherapy

3 → Yes, adjuvant (post-operative) chemotherapy

4 → Yes, both neoadjuvant and adjuvant chemotherapy

9 → Unknown/missing

- Targeted therapy, including monoclonal antibodies (Tt)

  Numeric variable, one digit.

  Definition: Targeted therapy comprises all drugs that block the growth of cancer cells by inhibition of certain pathways in the cancer cell. Traditional chemotherapy also affects other cells in the body that divide quickly. The main categories of targeted therapy are small molecules (mostly tyrosine kinase inhibitors such as imatinib and many other -nibs) and monoclonal antibodies (such as rituximab and many other -mabs). Monoclonal antibodies are considered a form of immunotherapy but should be coded as targeted therapy.

  Coding: It should be coded according to the following categories (Table 1):

  0 → No

  1 → Yes

  9 → Unknown/missing

- Immunotherapy, excluding monoclonal antibodies (It)

  Numeric variable, one digit.

  Coding: It should be coded according to the following categories (Table 1):

  0 → No

  1 → Yes

  9 → Unknown/missing

- Hormone therapy (Ht)

  Numeric variable, one digit.

  Coding: It should be coded according to the following categories (Table 1):

  0 → No

  1 → Yes

  9 → Unknown/missing

- Other or unspecified systemic therapy (Ot)

  Numeric variable, one digit.

  Coding: It should be coded according to the following categories (Table 1):

  0 → No

  1 → Yes, without other specification

  2 → Yes, neoadjuvant (pre-operative)

3 → Yes, adjuvant (post-operative)

9 → Unknown/missing

- Stem cell transplantation (SCT)

  Numeric variable, one digit.

  Coding: It should be coded according to the following categories (Table 1):

  0 → No

  1 → Yes

  9 → Unknown/missing

Table 1. Variable name, description, format, missing/unknown values and coding schema

Variables should be separated by a semi-colon

Patient variables					
Variable name	**Variable description**	**Format**	**Maximum length**	**Missing/ unknown**	**Coding**
PAT[1]	Patient identification code	A	50	Not allowed	According to registry coding
MoB	Month of birth	F	2	99	Range of allowed values: 1 - 12
YoB	Year of birth	F	4	9999	Range of allowed values: > 1842 and ≤ the current year
Sex	Sex at birth	F	1	9	1 →Male 2 →Female 3 →Other
Tumour variables					
Geo_code	Code for the geographical area of residence at Diagnosis	A	10	XX99	NUTS2 when available or the highest level of administrative sub-divison that can be provided[2]. Blank → not applicable
Geo_label	Name of the geographical area of residence at Diagnosis	A	50	9	Blank → not applicable
TUM	Tumour identification	A	50	Not allowed	According to registry coding
Age	Age at diagnosis (incidence date) in years	F	3	999	Range of allowed values: ≥ 0 and < 121
MoI	Month of incidence	F	2	99	Range of allowed values: 1 - 12
YoI	Year of incidence	F	4	Not allowed	Range of allowed values: From 1941 to present
BoD	Basis of diagnosis	F	1	9	0→Death certificate only 1→Clinical 2→Clinical investigation 4→Specific tumour markers 5→Cytology 6→Histology of a metastasis 7→Histology of a primary tumour
Topo	ICD-O-3 topography code	A	4	Not allowed	Valid code in ICD-O-3
Morpho	ICD-O-3 morphology code	F	4	Not allowed	Valid code in any ICD-O-3 version
Beh	ICD-O-3 behaviour	F	1	Not allowed	0→ Benign neoplasm 1→ Neoplasm of uncertain and unknown behaviour 2→ In situ neoplasm 3→ Malignant neoplasm
Grade[3]	ICD-O-3 grade of differentiation / immunophenotype	F	1	9	1→Grade I, Well differentiated 2→ Grade II, Moderately differentiated 3→ Grade III, Poorly differentiated 4→Grade IV, Undifferentiated, anaplastic 5→ T-cell; T-precursor 6→ B-Cell; Pre-B; B-precursor 7→ Null cell; Non T-non B 8→ NK cell (natural killer cell) 9→ Not applicable

[1] *PAT* should be a code assigned by the registry that is not to be used elsewhere (e.g. in a hospital). So, it cannot be an official personal number. It may be an encrypted personal number as long as this specific encryption is not used by any other organisation. The JRC will provide the tool to the CRs to do it.

[2] The geographical area for French CRs should be coded according to NUTS3 (see Note on page 8).

[3] The *grade* of tumours of the central nervous system should be coded according to table 27 of ICD-O-3.

Table 1. Variable name, description, format, missing/unknown values and coding schema

Variables should be separated by a semi-colon

Variables related to follow-up					
Variable name	**Variable description**	**Format**	**Maximum length**	**Missing/ unknown**	**Coding**
Autopsy[3]	Incidental finding of cancer at autopsy	F	1	9	0→No 1→Yes
Vit_stat	The last known vital status	F	1	9	1→ Alive 2→ Dead
MoF	Month of last known vital status	F	2	99	Range of allowed values: From 1 to 12
YoF	Year of last known vital status	F	4	9999	Range of allowed values: > 1941 and ≤ the current year
Surv_time	Duration of survival in days	F	5	99999	≥ 0
ICD[4,5]	ICD edition for coding cause of death	F	2	99	Range of allowed values: <12 Blank → Not applicable
CoD[4,5]	Official underlying cause of death	A	4	R99 (ICD-10) 7999 (ICD-9)	According to ICD Blank → Not applicable
Stage variables					
TNM_ed	TNM edition	F	2	99	Allowed values: ≤ 8
cT[6]	Clinical T-category	A	12	9	According to the TNM Classification of Malignant Tumours Blank → not applicable
cN[6]	Clinical N-category	A	12	9	
cM[6]	Clinical M-category	A	12	9	
pT[6,7]	Pathological T-category	A	12	9	
pN[6,7]	Pathological N-category	A	12	9	
pM[6,7]	Pathological M-category	A	12	9	
ToS	Staging system	A	3	9	A → Ann Arbor/ Lugano stage D → Dukes' stage E → Extent of disease F → FIGO stage S → TNM stage, unknown whether clinical or pathological clS → clinical TNM stage paS → pathological TNM stage cpS → combination of clinical & pathological TNM stage coS → condensed TNM stage esS → essential TNM stage T1 → Tier 1 stage for paediatric tumours T2 → Tier 2 stage for paediatric tumours 8 → Other staging system

[3] In autopsy cases, incidentally found at autopsy, the *vital status* is always 2 (dead) and the *survival* time is 0 days.

[4] If the vital status is 1 (alive) the *CoD* and *ICD* should be left blank;

[5] if the vital status is 2 (dead) and the cause of death is unknown, CoD should be coded as R99 (ICD-10)/7999 (ICD-9) or 9999 and ICD should be coded as 99

[6] If TNM is not available or not applicable, cTNM (*cT, cN, cM*) and pTNM (*cT, cN, cM*) should be coded as 9 and be left blank respectively and (if possible) *Staging system (ToS)* and *stage* should be coded.

[7] If cTNM is available and the primary tumour was not resected the pTNM (*pT, pN, pM*) should be left blank.

Table 1. Variable name, description, format, missing/unknown values and coding schema

Variables should be separated by a semi-colon

Variable name	Variable description	Format	Maximum length	Missing/ unknown	Coding
Stage variables					
Stage	Stage	F	1	9	0 → Stage 0, stage 0a, stage 0is, carcinoma in situ, non-invasive 1 → Stage I, FIGO I, localized, localized limited (L), limited, Dukes A 2 → Stage II, FIGO II, localized advanced (A), locally advanced, advanced, direct extension, Dukes B 3 → Stage III, FIGO III, regional (with or without direct extension), R+, N+, Dukes C 4 → Stage IV, FIGO IV, metastatic, distant, M+, Dukes D
Treatment variables					
Surgery[8,9]	Resection of the primary tumour	F	1	9	0 → No 1 → Yes, without specification 2 → Yes, local surgery only[a] 3 → Yes, 'operative' surgery[b]
Rt	Radiotherapy	F	1	9	0 → No 1 → Yes, without specification 2 → Yes, neoadjuvant (pre-operative) radiotherapy 3 → Yes, adjuvant (post-operative) radiotherapy
Cht	Chemotherapy	F	1	9	0 → No 1 → Yes, without other specification 2 → Yes, neoadjuvant (pre-operative) 3 → Yes, adjuvant (post-operative) 4 → Yes, both neoadjuvant and adjuvant
Tt[10]	Targeted therapy (including monoclonal antibodies)	F	1	9	0 → No 1 → Yes

[8] If available, type of surgery (*local surgery* [2] versus *operative surgery* [3]) should be coded for solid cancers of the following cancer sites: C01-C06, C16-C20, C30-C34, C53-C55, C61 and C65-C68. For other cancers, code 1 (surgery without specification) suffices.

[9] If both *local surgery* and *operative surgery* were performed for the same tumour, *operative surgery* should be coded.

[10] Targeted therapy comprises all drugs that block the growth of cancer cells by inhibition of certain pathways in the cancer cell. Traditional chemotherapy also affects other cells in the body that divide quickly. The main categories of targeted therapy are small molecules (mostly tyrosine kinase inhibitors such as imatinib and many other -nibs) and monoclonal antibodies (such as rituximab and many other -mabs). Monoclonal antibodies are considered a form of immunotherapy but should be coded as targeted therapy.

[a] The following procedures should be coded as local surgery: polypectomy (mainly gastro-intestinal tract), transurethral resection (TUR; bladder & other urinary tract), cone biopsy/loop excision (cervix), as well as all other procedures which leave the organ in situ, such as cryosurgery, laser coagulation, thermoablation, radiofrequency ablation (RFA), etc.

[b] This includes all resections of the tumor which require the removal of an organ or a major part of that organ, such as a lobectomy, hemicolectomy, hysterectomy, cystectomy, prostatectomy, etc.

Table 1. Variable name, description, format, missing/unknown values and coding schema

Variables should be separated by a semi-colon

Treatment variables					
Variable name	**Variable description**	**Format**	**Maximum length**	**Missing/ unknown**	**Coding**
It	Immunotherapy (excl. monoclonal antibodies)	F	1	9	0 → No 1 → Yes
Ht	Hormone therapy	F	1	9	0 → No 1 → Yes
Ot	Other or unspecified systemic therapy	F	1	9	0 → No 1 → Yes, without other specification 2 → Yes, neoadjuvant (pre-operative) 3 → Yes, adjuvant (post-operative)
SCT	Stem cell transplantation	F	1	9	0 → No 1 → Yes

3.2 Population file

Information on population data should be provided from official censuses, from intercensal/postcensal estimates provided by Vital Statistics Departments, or equivalent, or other official sources.

The population data should have the same geographical and temporal reference as for the cases of the incidence file.

Registries having cases belonging to more than one geographical area (Geo_code) need to send population data for each of the areas, specifying the reference area in the Geo_code variable as described next.

Scope

The population data should correspond to the cancer case file with respect to:

- registration area
- time period by year
- sex
- age-range
- Geo_code

Geo_code should refer to the same greographical areas included in the incidence file.

If possible, population figures should give the mid-year estimates for each sub-category.

File format

The population data should be submitted in the form of a text file with semi colon (;) separator, and should include headers with names as specified in examples 1 or 2.

The file should contain the following variables:

- Calendar year
- Sex
- Age: by single year of age, if possible, or otherwise 21 standard age ranges (see below)
- Geo_code
- Geo_label
- Number of residents

The variables in the population file should be in the same order as reported above.

If the population data are available by single year of age and, for example, the period for the cancer cases is 1992-2013, the population file should be provided as in EXAMPLE 1.

If population data are not available by single year of age, 21 age ranges should be provided by age-group as following: **0** (under 1 year), **1-4** (age group 1-4), **5-9** (age group 5-9), **10-14** (age group 10-14), **15-19** (age group 15-19), **20-24** (age group 20-24), **25-29** (age group 25-29), **30-34** (age group 30-34), **35-39** (age group 35-39), **40-44** (age group 40-44), **45-49** (age group 45-49), **50-54** (age group 50-54), **55-59** (age group 55-59), **60-64** (age group 60-64), **65-69** (age group 65-69), **70-74** (age group 70-74), **75-79** (age group 75-79), **80-84** (age group 80-84), **85-89** (age group 85-89), **90-95** (age group 90-95), **95+** (age group 95 and over). In this case, the population file should be provided as in EXAMPLE 2.

EXAMPLE 1

Calendar year	Sex	Age unit	Geo_ code	Geo_label	Number of residents
1992	1	0	AT11	Burgenland	$N_{1992,1,0}$
1992	1	1	AT11	Burgenland	$N_{1992,1,1}$
1992	1	2	AT11	Burgenland	$N_{1992,1,2}$
1992	1	3	AT11	Burgenland	$N_{1992,1,3}$
1992	…	…	…		…
1992	2	0	AT11	Burgenland	$N_{1992,2,0}$
1992	2	1	AT11	Burgenl and	$N_{1992,2,1}$
1992	2	2	AT11	Burgenland	$N_{1992,2,2}$
1992	2	3	AT11	Burgenland	$N_{1992,2,3}$
…	…	…			
2013	1	100	AT34	Vorarlberg	$N_{2013,1,100}$
2013	2	0	AT34	Vorarlberg	$N_{2013,2,0}$
2013	...	…	AT34	Vorarlberg	
2013	…	100	AT34	Vorarlberg	$N_{2013,2,100}$

Sex = 1 → males; Sex=2 → females

EXAMPLE 2

Calendar year	Sex	Age range	Geo_ code	Geo_label	Number of residents
1992	1	0	AT11	Burgenland	$N_{1992,1,1}$
1992	1	1-4	AT11	Burgenland	$N_{1992,1,2}$
1992	1	5-9	AT11	Burgenland	$N_{1992,1,3}$
1992	1	10-14	AT11	Burgenland	$N_{1992,1,4}$
1992	…	…	…		…
1992	2	0	AT11	Burgenland	$N_{1992,2,1}$
1992	2	1-4	AT11	Burgenland	$N_{1992,2,2}$
1992	2	5-9	AT11	Burgenland	$N_{1992,2,3}$
1992	2	10-14	AT11	Burgenland	$N_{1992,2,4}$
…	…	…			
2013	1	95+	AT34	Vorarlberg	$N_{2013,1,21}$
2013	2	0	AT34	Vorarlberg	$N_{2013,2,1}$
2013	...		AT34	Vorarlberg	
2013	…	95+	AT34	Vorarlberg	$N_{2013,2,21}$

Sex = 1 → males; Sex=2 → females

Accompanying information required

- Any other coding than the recommended above should be documented in the data call questionnaire (section 2).
- The reference to the source of population data should be provided in the data call questionnaire (section 2).
- The reference calendar data (e.g. 1st January, 31st December, etc) must be indicated in the data call questionnaire (section 2).

3.3 Mortality file

National CRs are NOT required to submit national mortality statistics, as these can be retrieved directly from the EUROSTAT or WHO databases.

For sub-national registries, mortality statistics are partially available either from the previous submission, or from EUROSTAT. Therefore sub-national registries need to complement the mortality statistics and submit mortality data according to the specifications detailed in ANNEX 2.

The mortality data should be the official cancer mortality data, as obtained from the Vital Statistics Department, or equivalent, and based on certificates/death records.

Mortality data will be published in the ECIS web application (https://ecis.jrc.ec.europa.eu/) and used to compute quality indicators.

Scope

The mortality data for the area covered by the CR should include all residents whose underlying cause of death was cancer.

The mortality data should correspond to the cancer cases file with respect to:

- registration area
- time period by year
- sex
- age-range.

File format

The mortality data should be submitted in the form of a text file with semi colon (;) separator, and include headers with names as specified in examples 3 or 4.

The file should contain the following variables:

- Calendar year
- Sex
- Age: single year of age, if possible, or otherwise 21 age range (see below)
- Cause of death: 3 digits of the applicable International Classification of Diseases (ICD)
- Number of deaths

The variables in the mortality file should be in the same order as reported above.

Overall mortality data for all ages combined (total number of deaths) is acceptable only if no breakdown information by age-group is available to the registry.

If the number of deaths is available by single year of age and, for example, the period for cancer cases is 1992-2013, the mortality file should be provided as in EXAMPLE 3.

Alternatively, the number of deaths for the combination of calendar year, sex, age range and cause of death should be provided (EXAMPLE 4), using the following age range codes: **0** (under 1 year), **1-4** (age group 1-4), **5-9** (age group 5-9), **10-14** (age group 10-14), **15-19** (age group 15-19), **20-24** (age group 20-24), **25-29** (age group 25-29), **30-34** (age group 30-34), **35-39** (age group 35-39), **40-44** (age group 40-44), **45-49** (age group 45-49), **50-54** (age group 50-54), **55-59** (age group 55-59), **60-64** (age group 60-64), **65-69** (age group 65-69), **70-74** (age group 70-74), **75-79** (age group 75-79), **80-84** (age group 80-84), **85-89** (age group 85-89), **90-95** (age group 90-95), **95+** (age group 95 and over).

EXAMPLE 3

Calendar year	Sex	Age unit	Cause of death	Number of Deaths
1992	1	0	C00	$N_{1992,1,0,C00}$
1992	1	1	C00	$N_{1992,1,1,C00}$
1992	1	2	C00	$N_{1992,1,2,C00}$
1992	1	3	C00	$N_{1992,1,3,C00}$
1992	…	…	…	…
1992	2	0	C00	$N_{1992,2,0,C00}$
1992	2	1	C00	$N_{1992,2,1,C00}$
1992	2	2	C00	$N_{1992,2,2,C00}$
1992	2	3	C00	$N_{1992,2,3,C00}$
…	…	…		
2013	1	100	C97	$N_{2013,1,100,C97}$
2013	2	0	C00	$N_{2013,2,0,C00}$
2013	…	…		
2013	…	100	C97	$N_{2013,2,100,C97}$

Sex = 1 → males; Sex=2 → females

EXAMPLE 4

Calendar year	Sex	Age range	Cause of death	Number of Deaths
1992	1	0	140	$N_{1992,1,1,140}$
1992	1	1-4	140	$N_{1992,1,2,140}$
1992	1	5-9	140	$N_{1992,1,3,140}$
1992	1	10-14	140	$N_{1992,1,4,140}$
1992	…			
1992	2	0	140	$N_{1992,2,1140}$
1992	2	1-4	140	$N_{1992,2,2,140}$
1992	2	5-9	140	$N_{1992,2,3,140}$
1992	2	10-14	140	$N_{1992,2,4,140}$
…	…			
2013	1	95+	208	$N_{2013,1,21,208}$
2013	2	0	140	$N_{2013,2,1,140}$
2013	…			
2013	…	95+	208	$N_{2013,2,21,208}$

Sex = 1 → males; Sex=2 → females

Accompanying information required

- Any coding, other than that recommended, should be documented also in the data call questionnaire (section 3).
- A reference to the source of population data should be provided in the data call questionnaire (section 3).

3.4 Life tables – ONLY for the European Cancer Information System (ECIS) and EUROCARE projects and for cancer registries providing follow-up and survival data

Life tables, i.e. the background mortality in the general population of the administrative territory covered by the cancer registry, must be provided by registries covering their entire period of incidence or the period in which the follow-up is available.

All-causes of **death probabilities** in the general population, **by sex, age and calendar year**, should be provided to **6 decimal** places or an equivalent number of significant figures (e.g. 0.012345 for a rate of 1,234.5 per 100,000). The format of all-causes of death information must be specified in the Questionnaire, where you state whether you are providing **probabilities** or **rates**. Since all-causes death probabilities are highly dependent on age, values should be **preferably** given by **one-year age classes** (from 0 to 99 or more). If this is not possible, age should be grouped by **no more than five years**: in this case, please specify how the life tables were smoothed in the data call questionnaire (section 4).

It is essential to have accurate all-causes death probabilities for the elderly to accurately estimate relative survival in this age group. The oldest age class can be open ended (e.g. 90 years and over), but the lower boundary of **the oldest age class should not be less than 85 years**.

Life tables should have the same geographical and temporal reference as for the cases of the incidence file. Registries having cases belonging to more than one geographical area (Geo_code) are invited to send life tables for each of the areas, if available, specifying the reference area in the Geo_code and Geo_label variables as described next. If available, **NUTS2 or the same administrative regions** used for incidence file should be provided.

Life tables are partially available from the previous submission. Registries need to complement their life tables according to the specifications detailed in ANNEX 3.

Please document the source of demographic data in the data call questionnaire (section 4).

EXAMPLE 5

Calendar year	Sex	Annual age (years)	Geo_code	Geo_label	All causes death probability
1990	1	0	AT11	Burgenland	0.003228
1990	1	1	AT11	Burgenland	0.000272
1990	1	2	AT11	Burgenland	0.000376
..	…	…	…	…	…
1990	1	99	AT11	Burgenland	0.414117
1990	2	0	AT11	Burgenland	0.000379
1990	2	1	AT11	Burgenland	0.000376
1990	2	2	AT11	Burgenland	0.000373
…	…	…	…	…	…
1990	2	99	AT11	Burgenland	0.389871
…	…	…	…	…	…
2013	1	0	AT34	Vorarlberg	0.002528
2013	...	…	…	…	…
2013	2	99	AT34	Vorarlberg	0.342862

Sex = 1 → males; Sex=2 → females
Geo_code: Code of the geographical area of residence at diagnosis
Geo_label: Name of the geographical area of residence at diagnosis (Geo_label)

3.5 Questionnaire

The questionnaire is an essential part of the data submission process and for data interpretation and comparability among registries.

CRs will be invited to fill in the questionnaire at the time of submission and this step will be a pre-requisite for the completion of the data submission process. The questionnaire is focused on the datasets submitted.

4. REFERENCES

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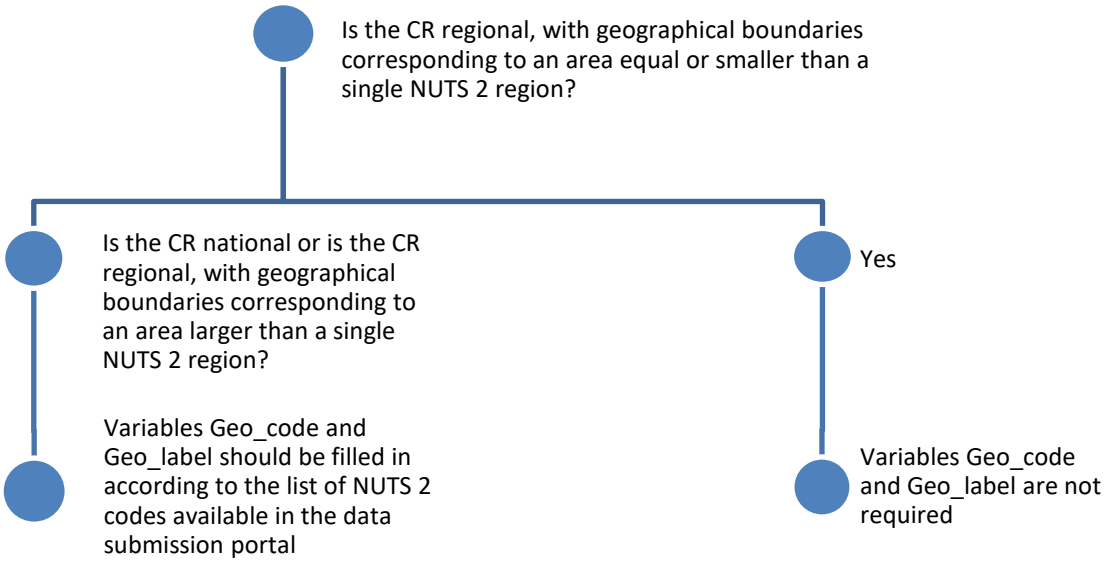
4. Percy C, Fritz A, Jack A, Shanmugarathan S, Sobin L, Parkin DM, Whelan S. International Classification of Diseases for Oncology (ICD-O). World Health Organization; 3 edition (December 2000). Available in: https://apps.who.int/iris/bitstream/handle/10665/96612/9789241548496_eng.pdf?sequence=1&isAllowed=y
5. ICDO- THIRD EDITION, SECOND REVISION MORPHOLOGY (ICD-O-3.2) available in: http://www.iacr.com.fr/index.php?option=com_content&view=category&layout=blog&id=100&Itemid=577
6. ENCR recommendations on urothelial tumours.
7. International Statistical Classification of Diseases and Related Health Problems, 10th Revision. World Health Organisation, 2011.
8. International Statistical Classification of Diseases and Related Health Problems, 9th Revision. World Health Organisation, 1977.

Annex 1 – Geographical variables

This section provides more information on how to fill in the Geo_code and Geo_label variables depending on whether the CR is national or regional.

The decision tree below relate to CR from EU-27 countries plus UK, as well as countries belonging to the European Free Trade Association (EFTA), candidate countries awaiting accession to the EU or potential candidates. A list of the regions and codes will be available in the CR-specific area of the Portal.



The scheme above refers to the incidence, population and life tables files. If Geo-code and Geo-label cannot follow the NUTS nomenclature as requested for the incidence file, please specify in the questionnaire which geographical areas are Geo-code and Geo-label refer to in the life table files.

For other European countries where the NUTS classification is not available, the Geo_code variable corresponds to the highest level of administrative sub-divison in the area covered by the cancer registry which can be provided. A list of these regions and codes will be available in the CR-specific area of the Portal.

Annex 2 – Mortality data available at JRC for regional registries which does not fit NUTS2

Cancer Registry	Country	Available MORTALITY	
		Years	Source
ACCHAGAAA9 - Aargau Cancer Registry	CH	2013-2013	Registry
ACCHBASAA9 -Basel Cancer Registry	CH	2008-2012	Registry
ACCHBERAA9 - Bern Cancer Registry	CH	2013-2014	Registry
ACCHFRIAA9 - Fribourg Cancer Registry	CH	1995-2013	Registry
ACCHGENAA9 - Geneva Cancer Registry	CH	1995-2014	Registry
ACCHGGLAA9 - Graubunden and Glarus Cancer Registry	CH	1995-2013	Registry
ACCHSGAAA9 - St. Gallen-Appenzell Cancer Registry	CH	1995-2013	Registry
ACCHTHUAA9 - Thurgau Cancer Registry	CH	2012-2013	Registry
ACCHTICAA9 - Ticino Cancer Registry	CH	1996-2013	Registry
ACCHVALAA9 - Valais Cancer Registry	CH	1995-2014	Registry
ACCHZENAA9 - Central Switzerland Cancer Registry	CH	2011-2013	Registry
ACCHZURAA9 - Zurich Cancer Registry	CH	1995-2013	Registry
ACCHZURAA9 - Zug Cancer Registry	CH	1995-2013	Registry
ACRSCSEAA9 - Central Serbia Cancer Registry	RS	2003-2012	Registry
EUCY999AA9 - Cyprus Cancer Registry*	CY	2004-2014	Registry
EUCYNCYAA9 - North Cyprus Cancer Registry	CY	No data	
EUESALBAA9 - Albacete Cancer Registry	ES	2008-2012	Registry
EUESBALAA9 - Balearic Islands Cancer Registry	ES	1988-2012	Registry
EUESCANAA9 - Canary Islands Cancer Registry	ES	1993-2011	Registry
EUESCASAA9 - Castellon Cancer Registry	ES	2000-2013	Registry
EUESCIUAA9 - Ciudad Real Cancer Registry	ES	2008-2012	Registry
EUESCUEAA9 - Cuenca Cancer Registry	ES	2008-2012	Registry
EUESGIRAA9 - Girona Cancer Registry	ES	1994-2015	Registry
EUESGRAAA9 - Granada Cancer Registry	ES	1985-2012	Registry

*Government controlled area

Cancer Registry	Country	Available MORTALITY	
		Years	Source
EUESTARAA9 - Tarragona Cancer Registry	ES	1982-2012	Registry
EUFRBRHAA9 - Bas-Rhin Cancer Registry	FR	1975-2013	Francim
EUFRBURDI9 - Bourguignon Digestive Cancer Registry	FR	1976-2013	Francim
EUFRCALAA9 - Calvados Cancer Registry	FR	1978-2013	Francim
EUFRCALDI9 - Calvados Digestive Cancer Registry**	FR	1978-2013	Francim
EUFRCOTBG9 - Cote d Or Breast and Gynaecologic Cancer Registry°	FR	1976-2013	Francim
EUFRCOTHE9 - Cote d'Or Hemopathy Registry°	FR	1976-2013	Francim
EUFRDOBAA9 - Doubs Cancer Registry	FR	1978-2013	Francim
EUFRDOBAA9 - Belfort Cancer Registry	FR	2007-2012	Francim
EUFRFINDI9 - Finistere Digestive Cancer Registry	FR	2005-2013	Francim
EUFRGIRAA9 - Gironde Cancer Registry	FR	2000-2013	Francim
EUFRGIRHE9 - Gironde Malignant Hemopathy Registry**	FR	2000-2013	Francim
EUFRGIRNS9 - Gironde Nervous System Cancer Registry**	FR	2000-2013	Francim
EUFRHERAA9 - Herault Cancer Registry	FR	1987-2013	Francim
EUFRHRHAA9 - Haut-Rhin Cancer Registry	FR	1988-2013	Francim
EUFRISEAA9 - Isere Cancer Registry	FR	1979-2013	Francim
EUFRLILAA9 - Lille Cancer Registry	FR	2008-2012	Francim
EUFRLIMAA9 - Limousin Cancer Registry	FR	2009-2013	Francim
EUFRLOIAA9 - Pays de la Loire Cancer Registry	FR	1991-2013	Francim
EUFRMADTH9 - Marne-Ardennes Thyroid Cancer Registry	FR	1975-2013	Francim
EUFRMANAA9 - Manche Cancer Registry	FR	1994-2013	Francim
EUFRNOBHE9 - Lower Normandy Hemopathy Registry	FR	1978-2013	Francim
EUFRPOCAA9 - Poitou-Charentes Cancer Registry	FR	2008-2013	Francim
EUFRSOMAA9 - Somme Cancer Registry	FR	1982-2013	Francim
EUFRTARAA9 - Tarn Cancer Registry	FR	1982-2013	Francim

**Covers the same area as the general Cancer Registry
°CRs are covering the same area

Cancer Registry	Country	Available MORTALITY	
		Years	Source
EUITBATAA9 - Barletta-Andria-Trani Cancer Registry	IT	2006-2012	Airtum
EUITBERAA9 - Bergamo Cancer Registry	IT	2007-2012	Airtum
EUITBIEAA9 - Biella Cancer Registry	IT	2008-2012	Registry
EUITBREAA9 - Brescia Cancer Registry	IT	1999-2010	Airtum
EUITBRIAA9 - Brindisi Cancer Registry	IT	2006-2008	Airtum
EUITCAIAA9 - Integrated Cancer Registry of Catania-Messina-Siracusa-Enna	IT	2003-2013	Airtum
EUITCASAA9 - Caserta Cancer Registry	IT	2008-2010	Airtum
EUITCATAA9 - Catanzaro Tumor Registry	IT	2003-2010	Airtum
EUITCOMAA9 - Como Cancer Registry	IT	2003-2011	Airtum
EUITCREAA9 - Cremona Cancer Registry	IT	2005-2010	Airtum
EUITEMIAA9 - Reggio Emilia Cancer Registro	IT	1996-2014	Airtum
EUITFERAA9 - Ferrara Cancer Registry	IT	1991-2011	Airtum
EUITFVGAA9 - Friuli Venezia Giulia Cancer Registry	IT	1995-2010	Airtum
EUITGENAA9 - Liguria Region Tumor Registry	IT	1986-2010	Airtum
EUITLATAA9 - Latina Cancer Registry	IT	1990-2012	Airtum
EUITLECAA9 - Lecce Cancer Registry	IT	2003-2008	Airtum
EUITLODAA9 - Lodi Cancer Registro	IT	2003-2012	Registry
EUITMACAA9 - Macerata Province Tumor Registry	IT	1991-2001	Airtum
EUITMANAA9 - Mantova Cancer Registry	IT	1999-2010	Airtum
EUITMBRAA9 - Monza and Brianza Cancer Registry	IT	2007-2012	Airtum
EUITMILAA9 - Milan Cancer Registry	IT	2008-2012	Airtum
EUITMODAA9 - Modena Cancer Registry	IT	1988-2013	Airtum
EUITNAPAA9 - Campania Cancer Registry	IT	1996-2013	Airtum
EUITNUOAA9 - Nuoro Cancer Registry	IT	2003-2012	Airtum
EUITPALAA9 - Palermo Cancer Registry	IT	2003-2013	Airtum
EUITPARAA9 - Parma Cancer Registro	IT	1987-2014	Airtum

Cancer Registry	Country	Available MORTALITY	
		Years	Source
EUITPAVAA9 - Pavia Cancer Registry	IT	2008-2010	Airtum
EUITPIAAA9 - Piacenza Cancer Registry	IT	2006-2014	Airtum
EUITRAGAA9 - Ragusa Cancer Registry	IT	1981-2012	Airtum
EUITROMAA9 - Romagna Cancer Registry	IT	1986-2014	Airtum
EUITSALAA9 - Salerno Cancer Registry	IT	1996-2010	Airtum
EUITSASAA9 - Sassari Cancer Registry	IT	1992-2011	Airtum
EUITSONAA9 - Sondrio Cancer Registry	IT	1998-2013	Airtum
EUITSTYAA9 - South Tyrol Cancer Registry	IT	1995-2010	Airtum
EUITSYRAA9 - Syracuse Cancer Registry	IT	1999-2012	Airtum
EUITTARAA9 - Taranto Cancer Registry	IT	2006-2012	Airtum
EUITTREAA9 - Trento Cancer Registry	IT	1995-2010	Airtum
EUITTRPAA9 - Trapani Cancer Registry	IT	2002-2010	Airtum
EUITTURAA9 - Piedmont-Turin City Cancer Registry	IT	2008-2012	Registry
EUITTUSAA9 - Tuscany Cancer Registry	IT	1985-2010	Airtum
EUITVARAA9 - Varese Cancer Registry	IT	1978-2012	Airtum
EUITVENAA9 - Veneto Cancer Registry	IT	1996-2010	Airtum
EUITVITAA9 - Viterbo Cancer Registry	IT	2006-2010	Airtum
EUPTAZOAA9 - Azores Cancer Registry°°	PT	1981-2013	Registry
EUPTCOIAA9 - Portugal Central Region Cancer Registry°°	PT	2008-2010	Registry
EUPTNOPAA9 - Portugal North Region Cancer Registry°°	PT	No data	-
EUPTSOLAA9 - Portugal South Region Cancer Registry°°	PT	No data	-
EUROCLUAA9 - Cluj Cancer Registry	RO	2008-2012	Registry
EUROTIMAA9 - Central Regional Timisoara Cancer Registry	RO	2008-2012	Registry
TCBASRPAA9 - Republic of Srpska Cancer Registry	BA	2008-2012	Registry
TCRUSAMAA9 - Samara Cancer Registry	RU	No data	-

°°Area is now covered by the National Cancer Registry

Annex 3 – Available life tables at the JRC

Note: Life tables available at the JRC from the 2015 submission do not contain geographical references (Geo_code and Geo_label). For the national cancer registries or regional registries with geographical boundaries corresponding to an area larger than a single NUTS2, please refer to the instructions in section Annex 1 for the update of the life tables – Geographical variables.

Cancer Registry	Available life table (years)
ACBY999AA9 -Belarusia National Cancer Registry	No data
ACCH999AA1- Swiss National Childhood Cancer Registry	1999-2013
ACCHAGAAA9 - Aargau Cancer Registry	2013
ACCHBASAA9 - Basel Cancer Registry	1981-2013
ACCHBERAA9 - Bern Cancer Registry	213-2014
ACCHFRIAA9 - Fribourg Cancer Registry	1981-2013
ACCHGENAA9 - Geneva Cancer Registry	1970-2013
ACCHGGLAA9 - Graubunden and Glarus Cancer Registry	1989-2013
ACCHSGAAA9 - St. Gallen-Appenzell Cancer Registry	1981-2013
ACCHTHUAA9 - Thurgau Cancer Registry	2012-2013
ACCHTICAA9 - Ticino Cancer Registry	1996-2013
ACCHVALAA9 - Valais Cancer Registry	1981-2013
ACCHZENAA9 - Central Switzerland Cancer Registry	All 2011-2013
ACCHZURAA9 - Zug Cancer Registry	1981-2013
ACCHZURAA9 - Zurich Cancer Registry	1981-2013
ACIS999AA9 - Iceland National Cancer Registry	2007-2014
ACME999AA9 - Montenegro Cancer Registry	2012
ACNO999AA9 - Norway National Cancer Registry	No data
ACRSCSEAA9 - Central Serbia Cancer Registry	No data
EUAT999AA9 - Austria National Cancer Registry	1983-2013
EUBE999AA9 - Belgium National Cancer Registry	2004-2014
EUBG999AA9 - Bulgaria National Cancer Registry	1993-2013
EUCY999AA9 - Cyprus Cancer Registry	2004-2013
EUCYNCYAA9 - North Cyprus Cancer Registry	No data
EUCZ999AA9 - Czech Cancer Registry	1994-2013

Cancer Registry	Available life table (years)
EUDE999AA1 - German National Childhood Cancer Registry	No data
EUDEBAVAA9 – Bavaria Cancer Registry	2003-2012
EUDEBBEAA9 - Common Cancer Registry of the federal states Berlin, Brandenburg, Mecklenburg-Western, Pomerania, Saxony-Anhalt and of the Free States of Saxony and Thuringia	1956-2013
EUDEBREAA9 - Bremen Cancer Registry	1998-2012
EUDEHAMAA9 - Hamburg Cancer Registry	1995-2013
EUDEHESAA9 - Hessen Cancer Registry	2007-2014
EUDENRWAA9 - North Rhine-Westphalia Cancer Registry	1995-2013 Only Münster District
EUDERHPAA9 - Rhineland-Palatinate Cancer Registry	1998-2012
EUDESAAAA9 - Saarland Cancer Registry	1992, 1995, 1998, 2001, 2004, 2007, 2010
EUDESALAA9 - Lower Saxony Cancer Registry	2003-2012
EUDESCHAA9 - Schleswig-Holstein Cancer Registry	1998-2011
EUDK999AA9 - Denmark National Cancer Registry	No data
EUEE999AA9 - Estonia National Cancer Registry	1995-2014
EUESALBAA9 - Albacete Cancer Registry	1991-2014
EUESASTAA9 - Asturias Cancer Registry	No data
EUESBALAA9 - Balearic Islands Cancer Registry	1995-2012
EUESBASAA9 - Basque Country Cancer Registry	1986-2013
EUESCALAA1 - Castilla y Leon Childhood Cancer Registry	2010-2016
EUESCANAA9 - Canary Islands Cancer Registry	1996-2013
EUESCASAA9 - Castellon Cancer Registry	2004-2012
EUESCIUAA9 - Ciudad Real Cancer Registry	No data
EUESCUEAA9 - Cuenca Cancer Registry	2008-2012
EUESGIRAA9 - Girona Cancer Registry	1985-2015
EUESGRAAA9 - Granada Cancer Registry	1985-2013
EUESMURAA9 - Murcia Cancer Registry	1985-2013

Cancer Registry	Available life table (years)
EUESNAVAA9 - Navarra Cancer Registry	1975-2013
EUESRIOAA9 - La Rioja Cancer Registry	No data
EUESTARAA9 - Tarragona Cancer Registry	2008-2013
EUESVALAA1 - Comunitat Valenciana Childhood Cancer Registry	2000-2013
FRANCIM	1989-2017 Age group = 15-99 By department (8, 14, 21, 25, 29, 33, 34, 38, 44, 50, 51, 59, 61, 67, 68, 71, 80, 81, 85, 87, 90)
EUGR999HE1 - Greece National Registry for Childhood Hematological Malignancies	No data
EUHR999AA9 - Croatia National Cancer Registry	2001-2013
EUHU999AA1 - Hungary National Pediatric Cancer Registry	1993-2015
EUIE999AA9 - National Cancer Registry Ireland	1991-2013
EUITBASAA9 - Basilicata Cancer Registry	2006-2016
EUITBATAA9 - Barletta-Andria-Trani Cancer registry	2006-2016
EUITBERAA9 - Bergamo Cancer Registry	2002-2016
EUITBIEAA9 - Biella Cancer Registry	No data
EUITBREAA9 - Brescia Cancer Registry	1999-2016
EUITBRIAA9 - Brindisi Cancer Registry	2006-2016
EUITCAIAA9 - Integrated Cancer Registry of Catania-Messina-Siracusa-Enna	2003-2016
EUITCASAA9 - Caserta Cancer Registry	2008-2016
EUITCATAA9 - Catanzaro Tumor Registry	2003-2016
EUITCOMAA9 - Como Cancer Registry	2003-2016
EUITCREAA9 - Cremona Cancer Registry	2005-2016
EUITEMIAA9 - Reggio Emilia Cancer Registro	1996-2016
EUITFERAA9 - Ferrara Cancer Registry	1991-2016
EUITFVGAA9 - Friuli Venezia Giulia Cancer Registry	1995-2016
EUITGENAA9 - Liguria Region Tumor Registry	1986-2016

Cancer Registry	Available life table (years)
EUITLATAA9 - Latina Cancer Registry	1990-2016
EUITLECAA9 - Lecce Cancer Registry	2003-2016
EUITLIGME9 - Liguria Mesothelioma Cancer Registry	1994-2016
EUITLODAA9 - Lodi Cancer Registro	No data
EUITMACAA9 - Macerata Province Tumor Registry	1991-2016
EUITMANAA9 - Mantova Cancer Registry	1999-2016
EUITMARAA1 - Marche Childhood and Adolescent Cancer Registry	1990-2016
EUITMBRAA9 - Monza and Brianza Cancer Registry	2006-2016
EUITMILAA9 - Milan Cancer Registry	2008-2016
EUITMODAA9 - Modena Cancer Registry	1988-2016
EUITNAPAA9 - Campania Cancer Registry	1996-2016
EUITNUOAA9 - Nuoro Cancer Registry	2003-2016
EUITPALAA9 - Palermo Cancer Registry	2003-2016
EUITPARAA9 - Parma Cancer Registro	1978-2016
EUITPAVAA9 - Pavia Cancer Registry	2008-2010
EUITPIAAA9 - Piacenza Cancer Registry	2006-2016
EUITPIEAA1 - Piedmont Childhood Cancer Registry	1974-2016
EUITRAGAA9 - Ragusa Cancer Registry	1981-2016
EUITROMAA9 - Romagna Cancer Registry	1986-2016
EUITSALAA9 - Salerno Cancer Registry	1996-2016
EUITSASAA9 - Sassari Cancer Registry	1992-2016
EUITSONAA9 - Sondrio Cancer Registry	1998-2016
EUITSTYAA9 - South Tyrol Cancer Registry	1995-2016
EUITSYRAA9 - Syracuse Cancer Registry	1999-2016
EUITTARAA9 - Taranto Cancer Registry	2006-2016
EUITTREAA9 - Trento Cancer Registry	1995-2016
EUITTRPAA9 - Trapani Cancer Registry	2002-2016
EUITTURAA9 - Piedmont-Turin City Cancer Registry	No data

Cancer Registry	Available life table (years)
EUITTUSAA9 - Tuscany Cancer Registry	1985-2016
EUITUMBAA9 - Umbria Cancer Registry	1994-2016
EUITVALAA9 - Aosta Valley Cancer Registry	2007-2012
EUITVARAA9 - Varese Cancer Registry	1976-2016
EUITVENAA9 - Veneto Cancer Registry	1987-2016
EUITVITAA9 - Viterbo Cancer Registry	2006-2016
EULT999AA9 - Lithuania Cancer Registry	2008-2012
EULV999AA9 - Latvia Cancer Registry	2000-2013
EUMT999AA9 - Malta National Cancer Registry	2000-2013
EUNL999AA9 - Netherlands Cancer Registry	1989-2013
EUPL999AA9 - Poland National Cancer Registry	1999-2013
EUPTAZOAA9 - Azores Cancer Registry	1997-2013
EUPTCOIAA9 - Portugal Central Region Cancer Registry	2007-2013
EUPTNOPAA9 - Portugal North Region Cancer Registry	2007-2011
EUPTSOLAA9 - Portugal South Region Cancer Registry	No data
EUROCLUAA9 - Cluj Cancer Registry	No data
EUROTIMAA9 - Central Regional Timisoara Cancer Registry	No data
EUSI999AA9 - Slovenia Cancer Registry	1983-2014
EUSK999AA9 - Slovakia National Cancer Registry	No data
EUUKERSAA9 - England Cancer Registry	1995-2013
EUUKNIRAA9 - Northern Ireland Cancer Registry	1993-2014
EUUKSCOAA9 - Scotland Cancer Registry	1975-2013
EUUKWALAA9 -Welsh Cancer Registry	2010-2013
OTUA999AA9 - Ukrainia National Cancer Registry	No data
TCBASRPAA9 - Republic of Srpska Cancer Registry	No data
TCRUSAMAA9 - Samara Cancer Registry	No data