Standard dataset for the European Network of Cancer Registries

Contents

Contact: ENCR Secretariat
JRC-ENCR@ec.europa.eu

Introduction

The data collected by a cancer registry are related to its functions and the time and circumstances under which it operates. The basic items to be collected remain (see appendix 1), with the exception of ethnic group, which is difficult or even impossible to collect in most European countries. Country of birth may be an alternative for ethnic group in European countries with a large migrant population.
With the expanding role of cancer registries in cancer control, quality assessment of cancer care, clinical and epidemiological research, additional and standardised data items are necessary. With the rapid growth of computerisation in the health care sector, many items may be collected by linkage to existing data sources, as part of routine operations and on an ad hoc basis. The wealth of available data may be at the expense of standardisation and thus comparability. At present the level of computerisation and the legal basis for access to and linkage with health data vary across Europe. Hence some registries will have to collect data actively, and their operations will be restrained by their financial capability. Other registries may face a similar problem by having access to ever growing volumes of data, but without the capacity to check the quality of the data.

Aim

The aim of the present revision of the recommendation for a minimum dataset is:

- to preserve the possibilities present today for comparisons between the European registries and the rest of the world;
- to build upon data definitions developed by the European Network of Cancer Registries for more in-depth, wide-scale European collaborative efforts;
- to identify variables that may support an expanded role of registries if linkage possibilities to wide-scale electronic health information systems do not exist, in order to combine such data with data from areas where linkage possibilities do exist; and
- to identify variables collected by registries through electronic data acquisition and the need to establish common/standard guidelines/rules for data collection, coding systems and quality control measures to assure the data comparability.

It must be emphasized that the rules set out by the IACR on multiple primary cancer apply also to the European Minimum dataset. Table 1 gives an overview of this dataset.
Depending on the possibilities and the available resources registries may collect additional items.

Table 1

Variable	**Comment**
Personal identification	Preferably a unique ID number, otherwise full name
Date of birth (dd/mm/yyyy)	
Sex at birth	Male/female/undetermined

Postal code, zip code	Needed for identification and for geographical based studies
Hospital(s) of diagnosis	
Incidence date	According to ENCR recommendations
Basis of the diagnosis	According to ENCR recommendations
Topography (primary site)	According to the latest version of ICD-O*
Laterality (left, right, bilateral)	Laterality should be recorded for all solid cancers in paired organs (salivary gland, nasal cavity, paranasal sinuses, lung, pleura, breast, ovary/fallopian tube, testis, kidney, renal pelvis, ureter, eye and adrenal gland) Bilateral cases in paired organs should be registered separately, except for bilateral cancers of the ovary/fallopian tube, nephroblastoma and neuroblastoma Laterality is optional for sarcomas and skin cancers of the extremities
Morphology, including behaviour code	According to the latest version of ICD-O*
Grade (differentiation grade, WHO grade, Gleason grade group)	According to the latest version of ICD-O* and/or WHO
Immunophenotype (T-cell, B-cell, NK-cell)	For lymphoid haematological malignancies
Stage	See table 2 for the recommended stage variables
Prognostic (tumour) factors, such as ER/PR and Her2 (breast cancer), Breslow thickness (melanoma), HPV-status (oral cavity, cervix, vulva), cytogenetic aberrations (CNS, sarcoma, haematological malignancies), etc.	According to ENCR recommendations
Primary treatment	According to ENCR recommendations
Hospital(s) of treatment	
Date and site(s) of recurrence/progression	According to ENCR recommendations
Vital status	Needed for the study of survival
Date of death or date of last follow-up (dd/mm/yyyy)	
Cause of death	According to the standard of the cause of death registration in the registration area

*Coding systems that are equivalent to ICD-O and enable conversion to the latest version of ICD-O (without loss of information), such as ICD11 extension codes are also acceptable

Table 2

Type of cancer	Recommended stage variables	Remarks
Solid cancers in adults	TNM classification of malignant tumours (UICC)	This includes (y)cTNM and (y)pTNM (if applicable) Essential TNM may be an alternative for poorly resourced registries FIGO stage for gynaecological tumours is optional A registry should keep record which edition of the TNM classification was used for which incidence year
Solid cancers in adults for which TNM is not applicable (excluding tumours of the central nervous system)	Extent of disease	Extent of disease should be classified as follows: Localized disease Locally advanced disease (invasion of neighbouring organs) Regional disease (spread of the tumour to regional lymph nodes) Metastatic disease
Paediatric tumours	Tier 2 of the Toronto consensus principles and guidelines	Tier 1 may be an alternative for poorly resourced registries
Lymphoma	Lugano classification	The Lugano classification is an updated version of the Ann Arbor classification
Haematological malignancies	International prognostic scoring systems	The scoring system is different for each haematological malignancy. For example, the IPI-score for diffuse large B-cell lymphoma requires information on age, Ann Arbor stage, performance status, serum LDH and extranodal involvement.

Appendix 1:

In the publication Cancer Registration: Principles and Methods, edited by O.M. Jensen, D.M. Parkin, R.MacLennan, C.S. Muir and R.G. Skeet (published in 1991) a table is included that gives an overview of the variables that should be collected by cancer registries:

Table 1. Basis information for cancer registries

Item no.	Item	Comments
The person		
	Personal identification [a]	
3	Name	According to local usage
4	Sex	
5	Date of birth or age	Estimate if not known
	Demographic	
6	Address	Usual residence
11	Ethnic group [b]	When population consists of two or more groups
The tumour		
16	Incidence date	
17	Most valid basis of diagnosis	
20	Topography (site)	Primary tumour
21	Morphology (histology)	
22	Behaviour	
35	Source of information	E.g., hospital record no., name physician

[a] The minimum collected is that which ensures that if the same individuals are reported again to the registry, they will be recognized as being the same person. This could also be a unique personal identification number

[b] Ethnic group is included here because it is important for most registries, especially in developing countries

Appendix 2: Working Group Members

Otto Visser (Director of Netherlands Cancer Registry, Co-chair of the ENCR SC)
Liesbet Van Eycken (Director of Belgium Cancer Registry, Co-chair of the ENCR SC)
Irmina Michalek (Lublin Cancer Registry, Poland)
Henna Degerlund (Finnish Cancer Registry)
Francesco Giusti (Belgium Cancer Registry)
Łukasz Taraszkiewicz (Greater Poland Cancer Center)
Luciana Neamtiu (JRC, Ispra, Italy)
Carmen Martos (JRC, Ispra, Italy)