Recommendations for a Standard Dataset for the European Network of Cancer Registries

Preamble:

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. However, 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 quality control measures.

The variables that today are needed for proper cancer registration in Europe will be labelled "essential", other variables that will support the monitoring role of the cancer registry as "optional". It should be made clear that Cancer Registries are working under the EU Directive on processing of personal data with the derogations for §7 and §8 where both health and ethnic group otherwise could prohibit a lawful operation. It must be emphasized that the rules set out by the IACR on multiple primary cancer apply also to the European Minimum dataset. It should also be made clear, that several of the variables listed in the Optional section, cannot be collected meaningfully in many settings, and an attempt should only be made if a trial/pilot have demonstrated that data will be complete and valid for a large majority of the cases – i.e. in the order of 75-80%.

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Essential variables:

Item	Comment
THE PERSON	
Personal identification	In some countries a unique ID number, in others full name combined with date of birth & sex
Date of birth	Given as day, month and year (dd/mm/yyyy)
Sex	Male (M) or Female (F)
Ethnic group	As the population mixture increases this variable will increase in importance also to study inequality. [May be difficult to agree a classification which can be applied across the whole of Europe]
Address including postal (or zip) code	Needed for ID purpose and for geographical based studies
Vital status & date	It may be of value to indicate whether known or assumed (e.g. based on linkages to death certificates) (dd/mm/yyyy)
Date of death	Needed to study survival and follow-up (dd/mm/yyyy)
Last follow-up date	Needed to study follow-up (dd/mm/yyyy). Registry should indicate whether date refers to active or passive follow-up.
THE TUMOUR	
Incidence date	This date should be given priority as outlined by the ENCR recommendations as indicated here A-D. *(Optional: In order to have comparability more dates should be collected, preferably all included in the definition)*
A: Date of first histological/cytological confirmation of the tumour	Date of biopsy or date of pathology or date of pathology report (dd/mm/yyyy)
B: Date of first hospital admission or contact	May be the date of first out-patient visit for the disease (dd/mm/yyyy)
C: Other date of diagnosis	e.g. GP visit (dd/mm/yyyy)
D: Date of death	For cases discovered at death/autopsy or unknown (dd/mm/yyyy)
Primary tumour site	This should as a minimum be according to the ICD-O
Laterality	This should be recorded for all paired organs, but as a minimum for breast, eye, ovary, testis and kidney (but observe the multiple primary rules)
Primary tumour histology	This should as a minimum be according to the ICD-O

THE TUMOUR (continued)	
Behaviour	This should as a minimum be according to the ICD-O
Basis of diagnosis	Although the most valid is recommended, it is advised to record all relevant methods used separately. The basis should follow the recommended ENCR layout into microscopic, non-microscopic, and tumour markers.
Stage – (condensed TNM)	Stage is needed for pan-European studies and for servicing clinicians. It is recommended to use the ENCR condensed TNM.
Initial therapy (i.e. initiated within 4 month from incidence date) [A clear manual on what is included should be available form the registry for all treatment items]	As a minimum the registries should be able to present on a yes/no basis the treatment modalities used
Surgery	Any surgical procedure of curative or palliative nature
Radiotherapy	Any radiotherapy of curative or palliative nature
Chemotherapy	Any cancer chemotherapy of curative or palliative nature
Endocrine (hormones)	Exogenous therapy i.e. medication
Source of information	It is important to record the source of information (hospital/institution) for each diagnosis and treatment modality in order to be able to do quality control, or to collect additional information. Also this will be the registry's receipt for not inventing data.

Optional variables:

THE PERSON	
Occupation	Since most cancer patients will be pensioned it should be the longest/last occupation if not a full occupational history is available
Industry	
Marital status	At the incidence date
Smoking status at diagnosis	Current, ex-smoker, non.smoker
Causes of death	Underlying, plus contributing (can be generated by record linkage in some places)
Place of death	
THE TUMOUR	
Mode of detection	Especially if screen detected as part of programme
Therapy details	Type of surgery Chemotherapy regimes Radiation fields – and radiation type Specification of endocrine therapy Record whether the given therapy was intended to be curative or not
Differentiation	As indicated in the ICD-O manual
Grade	For bladder tumours – grade at date of diagnosis
Recurrence	dd/mm/yyyy
Metastasis	Site of metastasis and date of diagnosis (dd/mm/yyyy) or as minimum – local, regional or distant metastasis and date of diagnosis (dd/mm/yyyy)
TNM – full, FIGO, Ann-Arbor etc.	If the registry has easy access to the full TNM or other stage classifications these should be recorded
FOLLOW-UP	
Follow-up	Clinical follow-up information – quality of life
Rehabilitation	Active programme/activities should be recorded
Palliation	Palliative activities should be followed