Appendix 2

Structured reviews of cancer registries

This is a service of ENCR to cancer registries which wish to have their performance evaluated. A standard structured review process is applied. Positive and negative aspects of a registry's procedures and outputs are identified, taking account of available resources.

It is a fundamental principle that the review should be a constructive, non-threatening experience aimed at helping registries to improve their performance, in some cases by providing independent, objective evidence of a need for additional resources. In some instances, the review may be able to assist in removing legal or organizational obstacles to registration.

A request for a structured review will normally be made by the funding body or host institution, but could also come from the cancer registry itself. Requests should be made to the ENCR Secretariat. A review team (normally consisting of two external experts, plus one person from the ENCR Secretariat) is selected by the Steering Committee and the Secretariat. The questionnaire presented on the following pages is completed by the registry and is reviewed by the team, which subsequently spends about two days in the registry. A review report is prepared.

There is no charge for the review itself. However, the inviting body is expected to meet the travel and other expenses of the review team.

ENCR REGISTRY REVIEW QUESTIONNAIRE

Please try to answer each question comprehensively, if appropriate, making use of your responses to previous questionnaires (e.g. for Cancer Incidence in Five Continents). When asked to provide additional information which cannot be incorporated in this electronic questionnaire (e.g., a data flow diagram, charts of age-standardized incidence rates, etc.), it would be helpful if an electronic copy of the information could be provided.

SECTION 1 - GENERAL ISSUES

1.1 Describe the area covered by your registry, in terms of the population (administrative unit, size, proportion of national population covered and distribution by age, socio-economic status, ethnicity and urban-rural residence), and main industries/occupations. Please provide a map of your country, indicating the area covered by your registry.

1.2 Provide a brief description of your country's health care system, particularly as it relates to cancer services (including prevention and screening).

1.3 What year was your registry established? Describe any major changes in the operation of the registry since its establishment (give dates of any significant milestones, e.g., death records becoming routinely available).

1.4 What legislation applies to cancer registration in your country (e.g., is it a statutory function, data protection, etc.)?

1.5 How do you define the purpose of your registry?

1.6 What are the arrangements for funding your registry?

1.7 Please provide a breakdown of your registry staff in terms of numbers of individuals, numbers of whole-time equivalents and job titles/functions (if possible, in the format of an organisation chart). Please distinguish between permanent staff and staff on short-term contracts. *(Please attach separate sheet)*

1.8 Please summarize your registry's arrangements for training of new staff and continuous professional development of existing staff.

1.9 Please provide a copy of any internal data confidentiality, data protection, and data security guidelines which apply to your registry. *(Please attach)* If the registry uses e-mail and internet, please indicate how you deal with data protection in this context.

1.10 Please provide copies of your registry's guidelines and form(s) relating to release of data and/or linkage to other databases. *(Please attach)*

1.11 Please describe the arrangements in place for obtaining permission to carry out research projects, both for in-house projects and for external researchers (including arrangements for review by research ethics committees).

1.12 Please indicate what you feel to be the strengths and weaknesses of your registry (if any). If you have identified any weaknesses, how do you feel they could be addressed?

SECTION 2 - DATA COLLECTION, DATA PROCESSING AND DATA QUALITY

2.1 What method of data collection is used in your registry?

☐ Active ☐ Passive ☐ Automated **What is the frequency?** _____

2.2 Please indicate the data sources which you use routinely to *identify* registrations or potential registrations, e.g.:

hospital discharge records	☐	hospital medical records	☐
histopathology records	☐	hospice records	☐
cytopathology records	☐	private hospital records	☐
haematology records	☐	radiology records	☐
radiation oncology records	☐	primary care records	☐
medical oncology records	☐	other cancer registries	☐
death records	☐	other _____	☐
autopsy records	☐		

2.2 Please indicate which of these records are theoretically available routinely for every case in your catchment area, and which are only available sporadically or only provide partial coverage of your catchment area.

	Routinely	*Sporadically*		*Routinely*	*Sporadically*
hospital discharge records	☐	☐	hospital medical records	☐	☐
histopathology records	☐	☐	hospice records	☐	☐
cytopathology records	☐	☐	private hospital records	☐	☐
haematology records	☐	☐	radiology records	☐	☐
radiation oncology records	☐	☐	primary care records	☐	☐
medical oncology records	☐	☐	other cancer registries	☐	☐
death records	☐	☐	other _____	☐	☐
autopsy records	☐	☐			

2.3 Please indicate which of your available data sources are in electronic form and which are paper-based.

	Electronic	*Paper*		*Electronic*	*Paper*
hospital discharge records	☐	☐			
histopathology records	☐	☐	hospital medical records	☐	☐
cytopathology records	☐	☐	hospice records	☐	☐
haematology records	☐	☐	private hospital records	☐	☐
radiation oncology records	☐	☐	radiology records	☐	☐
medical oncology records	☐	☐	primary care records	☐	☐
death records	☐	☐	other cancer registries	☐	☐
autopsy records	☐	☐	other _____	☐	☐

2.4 Are there any major data sources which are not available to you for practical reasons or because of restrictive legislation?

2.5 Please describe the way you collaborate with the different centres identifying the cancer patients. Do you monitor the notification routine (by region/district/hospital/pathology laboratory)?

2.6 Please describe your registration method (eg, entirely automated, entirely manual, mixed) and provide a data flow diagram which incorporates your available data sources, and summarises the registry processes. *(Please attach data flow diagram)*

2.7 Do you ever make registrations based on one source only (excluding DCOs)?

2.8 Please list any records which you use to *verify* potential registrations identified by other sources. Approximately what proportion of registrations are verified using these records?

2.9 Do you routinely monitor indicators of data quality (e.g., %MV, %DCO) in your registry and by region/district?

2.10 Describe briefly the validation checks in place in your registry (e.g., the IARC Check program)

2.11 How are records relating to a single individual linked to each other?

2.12 How do you record multiple tumours and how do you link them?

2.13 How is conflicting information from one or more sources reconciled?

2.14 What procedures are in place to minimize the risk of duplicate registration? How often is the registry database checked for duplicate registrations and how is this achieved?

2.15 Which classification(s) do you use for coding diagnosis (eg, ICD-O, ICD-10, etc.)? If classification has changed during the existence of the registry, please indicate which classification was used for which period.

2.16 Who is/are responsible for coding of the diagnosis of registered cases?

2.17 Do you follow up registered patients for vital status?

2.18 How does your registry define the incidence date?

2.19 When is a patient considered alive, dead or lost to follow-up?

2.20 Describe the data sources and procedures used to follow up patients for vital status. How often is this being done?

2.21 What is the most recent 'closing date' (i.e. the last date on which the vital status was confirmed for all patients)?

2.22 Can your registry identify patients who have subsequently emigrated, and their dates of emigration?

2.23 If you receive information about a person who is resident in the catchment area of another cancer registry, do you regularly pass this on? If so, how often and when was the last time you did so?

2.24 Do you receive information on patients resident in your registration area but diagnosed or treated elsewhere? Please give details on how you deal with this.

2.25 Please provide a brief description of your registry computer system indicating the operating system, database, network and application software.

2.26 Who supplied the computer application?

2.27 Is the computer application documented?

2.28 Who maintains the computer hardware and software?

2.29 How often are the contents of the registries' databases backed-up to external media?

2.30 Is the back-up medium stored/archived off-site and if so, how often?

2.31 If applicable, what does your registry use e-mail and the internet for. If you have a webpage please provide the address.

2.32 Please supply a copy of your registry's data definitions and any additional registration guidelines for staff. ***(Please attach documents)***

2.33 Does your registry collect staging information for any tumours? ☐ yes ☐ no

If so, please indicate:

Tumours for which you collect staging information	Year you started collecting this information	Staging classification used	% recorded as unknown stage in most recent available year of data

2.34 Please provide the following information for the following selected cancers:

Oesophagus (ICD9 150; ICD10 C15)
Stomach (ICD9 151; ICD10 C16)
Colon and rectum (ICD9 153 + 154; ICD10 C18 – C21)
Liver (ICD9 155; ICD10 C22)
Pancreas (ICD9 157; ICD10 C25)
Trachea, bronchus and lung (ICD9 162; ICD10 C33 + C34)
Bone (ICD9 170; ICD10 C40 + C41)
Malignant melanoma of skin (ICD9 172; ICD10 C43)
Female breast (ICD9 174; ICD10 C50 + sex = female)
Brain (ICD9 191; ICD10 C71)

(a) Percentage of death certificate only (DCO) records (as defined in *Comparability and Quality Control in Cancer Registration* (Parkin *et al.*, 1994)). By age group and crude total. *(Please attach table)*

(b) Percentage of microscopically verified (MV) records (as defined in *Comparability and Quality Control in Cancer Registration* (Parkin *et al.*, 1994)). By age group and crude total. *(Please attach table)*

(c) Mortality/incidence (M/I) ratios (as defined in *Comparability and Quality Control in Cancer Registration* (Parkin *et al.*, 1994)).

Oesophagus	_____
Stomach	_____
Colon and rectum	_____
Liver	_____
Pancreas	_____
Trachea, bronchus and lung	_____
Bone	_____
Malignant melanoma of skin	_____
Female breast	_____
Brain	_____

(d) Charts showing annual age-standardized incidence and mortality rates separately for males and females for the longest time period available (including the most recent year for which incidence data are believed to be essentially complete). Please specify the standard population used (World or European). *(Please attach charts)*

(e) Tables showing relative survival (%) at five years, by sex for consecutive five-year periods of diagnosis covering the longest time period available. *(Please attach tables)*

2.35 Has your registry (or anyone else) undertaken any recent detailed assessments of completeness of case ascertainment (e.g., using the independent comparison method, capture-recapture, etc.)? If so, please provide details of the methods used and a summary of the results. ***(Please attach summary of results)***

2.36 Has your registry (or anyone else) undertaken any recent detailed assessments of data validity either by using the reabstraction method or through validation of registry data in the course of a research or clinical review project? If so, please provide details and a summary of the results. ***(Please attach summary of results)***

SECTION 3 - USE OF DATA AND OUTPUT

3.1 Is any effort made to inform patients and the public of the existence of the cancer registry and the uses of the data? If so, how is this achieved?

3.2 What arrangements do you have for feeding back information to clinicians (both regionally and nationally)?

3.3 Please provide a list of groups you regard as having regular contact with your registry (eg, state and local health authorities, clinicians, researchers, charities and the voluntary sector, politicians, the media, patient organizations, the lay public, etc.). Approximately how often do you have contact with each of these?

3.4 Please provide a list of all peer-reviewed publications by your registry or involving members of its staff in the last two years. ***(Please attach)***

3.5 Please provide a list of all registry publications (e.g. annual reports) in the last two years, including electronic publications. Please indicate the intended audience for each type of publication. ***(Please attach)***

3.6 Do you have any evidence that your registry publications are used (e.g., from unsolicited feedback, questionnaire surveys, citation in other publications, etc)? If so, please give details.

3.7 How many *ad hoc* requests for information did your registry receive in the most recent complete calendar year?

3.8 Do you have a systematic research programme or plan for registry output and, if so, how far into the future does it extend?

3.9 Please provide a summary of your registry's current research portfolio. For each project, please indicate the sources of funding and the collaborators, if any (name and institute). *(Please attach)*

3.10 Does your registry undertake survival analysis?

3.11 In which international studies/databases have you participated? If you decided not to participate in a project, please give the reasons for this.

Name	Period(s)
CI5	
IICC	
EPIC	
EUROCIM	
EUROCARE	
EUROCLUS	
ACCIS	
Other	