EUROPEAN NETWORK OF CANCER REGISTRIES

STANDARD STRUCTURED REVIEW OF A CANCER REGISTRY

RECOMMENDATION FOR TEMPLATE OF THE REVIEW REPORT [1]

I.   GENERAL ISSUES

Name of the experts:

Dates start/end of the visit:

The report is based on [*the information, provided in the pre-visit questionnaire, review of the cancer registry documents, analysis of data file and interviews with cancer registrars and hospital staff...*]

List of Institutions, Organizations and Hospitals visited:..............

II.   BACKGROUND INFORMATION

1. POPULATION
2. HEALTH CARE SYSTEM, CANCER CARE AND MAIN RISK FACTORS
3. CANCER BURDEN

III.   PURPOSE OF THE REPORT

IV.   EVALUATION OF THE CANCER REGISTRY (CR)

1. REGISTRY NAME, CONTACT DETAILS AND BRIEF HISTORY
2. LOCATION
3. STAFF
4. SOURCE OF FINANCE
5. SOURCES OF INFORMATION
6. METHODS OF REGISTRATION
7. DATA MANAGEMENT AND DATA PROTECTION
8. LINKAGE WITH CLINICAL AND OTHER DATABASES
9. ITEMS OF INFORMATION, COLLECTED BY CR
10. DATA REPORTING
    a. Annual reports

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[1] The recommendation for template of the report is based on the document „ENCR Working Group on Structured Reviews of Cancer Registries", 2000.

Table 1. Availability of recommended component of the annual cancer incidence report [2]

No	Recommended component	Check if available in the report
	Background information	
1	Outline of the organisation of the cancer registry	
2	List of the professional staff	
3	Description of the reporting procedures	
4	Description of the sources of cases	
5	A list of reportable diseases	
6	Description of coding procedures	
7	A clear statement of definitions used in reporting	
8	Population covered by registration	
9	Reference for the population denominator data	
10	Description of statistical terms and methods	
11	Evaluation of findings: consistency of the number of cases in each calendar year	
12	Evaluation of findings: site distribution	
13	Evaluation of findings: indices of validity of diagnosis	
14	Evaluation of findings: demographic data	
15	Evaluation of findings: differences compared with similar areas	
	Tabular presentation	
16	Clearly defined contents of the table and the items	
17	Denominator for rates	
18	Frequency distribution in full	
19	Rate or proportion with the number of observations	
20	Particulars and criteria of exclusions	
21	Number of cases by site, age and sex	
22	Annual incidence rates by site, age and sex	
23	Age-standardised rates	
24	Cumulative incidence rates	
25	Tables for subsets of the population	
26	Tables for indices of the validity of diagnoses	
	Graphical presentation	
27	Limited amount of data per graph	
28	Tabular information for the graphs must be presented	
29	Appropriate choice of scale	
30	Graphs should form self-contained units	
31	Appropriate use of bar, pie and line graphs	

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[2] Jensen OM, Storm HH. Reporting of results. In: Jensen OM, Parkin DM, MacLennan R, Muir CS, Skeet RG. Cancer registration: principles and methods, IARC Scientific Publications No. 95, Lyon, 1991

b. Special reports, projects and publications
c. Website and data requests

11. COMPARABILITY

Comparability is the extent to which coding and classification procedures at CR adhere to agreed international guidelines[3].

Classifications and rules, applied at CR, are:

- Topography:
- Morphology:
- Behavior:
- Incidence Date:
- Basis of diagnosis:
- Multiple primaries:
- Stage at diagnosis:

In general, the review of the routines in place at the CR, indicated that they are/aren't according to the agreed International and European standards and guidelines for cancer registration, especially/concerning………

12. COMPLETENESS

Completeness is the extent to which all diagnosed cancer cases in the population are included in the CR database[4]. It is examined, as follows:

- <u>Incidence trends</u>
- <u>Comparison of incidence between populations</u>
- <u>Age-specific curves</u>:

Colorectal cancer
Bones tumors
Breast cancer
Cervical cancer
Testicular cancer
Thyroid cancer
Hodgkin disease

The described shapes of age-specific curves mainly correspond/or not to the expected ones for these sites.

- <u>Childhood cancer incidence</u>

The possibility of under registration or duplicates in childhood age groups can be investigated by comparing the observed age-specific rates in the childhood age range with an 'expected' range of

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[3] Bray F, Parkin DM. Evaluation of data quality in the cancer registry: Principles and methods. Part I: Comparability, validity and timeliness. EJC 2009, 45:747-55

values[4]. The limiting values for the lowest and highest deciles, published in Vol. VIII of CI5 are shown in Table 2.

Table 2. Age-specific incidence rates per 100 000 for childhood cancer by gender, for CR				
age (years)	boys		girls	
	CR	reference	CR	reference
0-4		12.3 - 24.7		9.7 - 21.4
5-9		8.5 - 15.6		6.9 - 12.0
10-14		8.5 - 15.0		6.8 - 13.6

- Mortality:incidence ratios

- Number of sources/notifications per case

- Morphologically verified diagnoses (MV%)

- Independent case ascertainment

- Capture-recapture methods

- DCN/M:I method

- The „flow" method

- Other methods

Completeness of registration was evaluated by the following methods:…
The results showed that…

13. VALIDITY

Validity is defined as the proportion of cases in CR with a given characteristic which truly have this attribute. Validity measures, used in this report are as follows:

- Reabstracting and recoding
- MV%
- Death certificate only (DCO%)
- Missing information
  - Topography unspecified (PSU%): C80, C26, C39, C48, C76 (ICD)

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[4] Parkin DM, Bray F. Evaluation of data quality in the cancer registry: Principles and methods. Part II. Completeness. EJC 2009, 45:756-64

- Morphology unspecifed (8000 – 8004, ICD)
- Stage unspecified
- Unknown gender, age, residency, date of diagnosis
- Internal consistency

Validity measures can be better interpreted when compared with an "expected" value reasonable for the region so that the values that are significantly different can be identified[5].

The observed validity measures are/aren't within the expected limits.

14. TIMELINESS

Timeliness refers to the rapidity at which a registry can collect, process and report sufficiently reliable and complete cancer data. It can be evaluated in terms of the time from diagnosis to registration, and the time from registration to the reporting of incidence (via the annual report). Another way is to evaluate the difference in number of cases, published in the annual report for one year, with the number of cases for the same year, available in the database one or two years after the publication.

The underreporting, due to publication before complete data collection, might be corrected by publishing a summary report for two or three years.
The evaluation of timeliness showed that…..
In conclusion: The review of the cancer registry showed that…..

V. RECOMMENDATIONS

- Data collection

- Data quality

- Information system

- Reporting

- Training

- Other

VI. PROPOSAL FOR:
- Short-term actions

- Long-term actions

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[5] Shin HR, Curado MP, Ferlay J, Heanue M, Edwards B, Storm H. Chapter 5: Comparability and quality of data. In: Curado MP, Edwards B, Shin HR, Storm H, Ferlay J, Heanue M, Boyle P (eds.) Cancer Incidence in Five Continents, Vol. IX. IARC Scientific Publication No. 160, Lyon, 2007