Making the population-based cancer registry heard – reporting the results

A key objective of a cancer registry is to produce statistics on the occurrence of cancer in a defined population. This information can be disseminated by different means, such as cancer incidence reports, cancer registry websites, research articles, and press releases, as well as through direct communication with clinicians, health authorities, the media, and other data users.

The cancer incidence report is the routine and baseline means of presenting registry data. These reports contain information on all reportable cancers and represent the main deliverable of a cancer registry, providing feedback to the stakeholders and the data providers. Even though cancer incidence does not vary markedly on an annual basis, most cancer registries are required by their stakeholders to publish new data annually. However, the registries with smaller populations and low yearly counts of rare cancers might choose to publish more detailed reports at longer intervals (e.g. 2 years or 5 years).
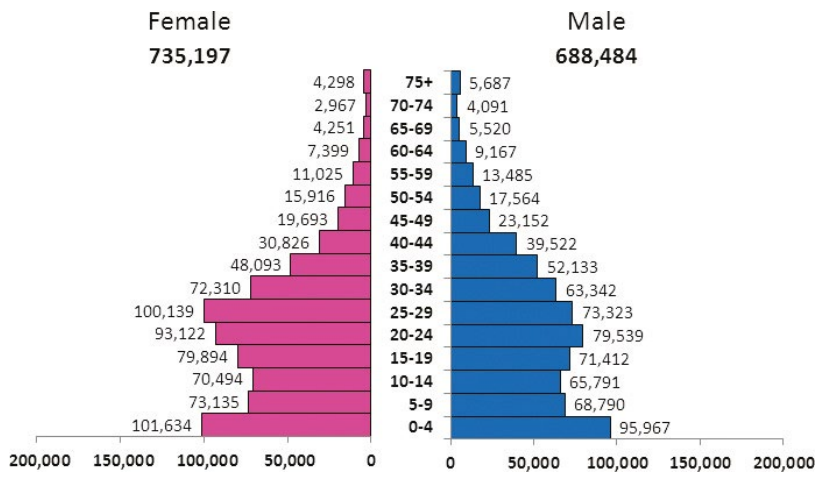
1. Basic contents of the report

Even though more and more cancer registries publish their data online, printed reports are still widely used. Therefore, the appearance (cover page) and size of the report should be considered. The initial pages of the report typically contain: name and address of the cancer registry (contact numbers, website, logo, etc.), names and designations of registry staff and members of the advisory committee, funding agency, date of the report, and table of contents. Stakeholders, for example the ministry of health, might be asked to contribute a foreword to the cancer registry report. Thereafter, a short executive summary of the report should be provided. The main components of the report are background information, evaluation and presentation of the results, and the tabular section.

1.1 Background information

This section should contain a brief description of the registry and registration procedures, in particular concerning classifications, rules, and definitions applied. The area and population covered should be described, and population counts should be presented in tabular or graphical format (e.g. Fig. 6.1). Sources of population estimates or data should be listed, and important demographic characteristics, such as ethnicity or religion, described. This section should also contain a description of data sources and a list of reportable diseases. Statistical

Fig. 6.1. Estimated average annual population of Harare City for the period 2010–2012. Source: Harare Cancer Registry Triennial Report, 2010–2012.

Female 735,197	Age	Male 688,484
4,298	75+	5,687
2,967	70-74	4,091
4,251	65-69	5,520
7,399	60-64	9,167
11,025	55-59	13,485
15,916	50-54	17,564
19,693	45-49	23,152
30,826	40-44	39,522
48,093	35-39	52,133
72,310	30-34	63,342
100,139	25-29	73,323
93,122	20-24	79,539
79,894	15-19	71,412
70,494	10-14	65,791
73,135	5-9	68,790
101,634	0-4	95,967

methods used for calculation of rates should be described and referenced.

1.2 Presentation of the results

Cancer registry tables are usually included as an annex to the report. The basic table is a frequency distribution of the number of cases during a specified time period according to the cancer site, age, and sex. The distribution should be given by 5-year age groups and by three-dig-it ICD level. This table should be accompanied by a similar table providing the age-, sex-, and site-specific annual rates. In addition to the age-specific information, this table should also contain crude, cumulative, and age-standardized rates. The guidelines for tabular presentation of the data (Hill, 1971) are summarized below:

• The contents of the table as a whole and the items in each separate column should be clearly and fully defined.

• If the table includes rates, the denominator on which they are based should be clearly stated.

• The frequency distributions should be given in full.

• Rates or proportions should not be given alone without any information as to the number of observations upon which they are based.

• Full particulars of any deliberate exclusions of registered cases must be given, with the reasons for and the criteria of exclusion being clearly defined.

As well as a tabular presentation, the reports should contain well-drawn and clear graphical depictions of selected results. Commonly these include the frequencies of different cancers or the ranking of age-standardized rates of the most common cancer sites (as bar graphs or pie charts) and the rates by age of different cancers or the trends of a given cancer over a calendar period (as line graphs). Commonly used graphs

Fig. 6.2. Ten most frequent cancers in males (percentages) in Malaysia in 2007. Source: Malaysia Cancer Registry Report, 2007.
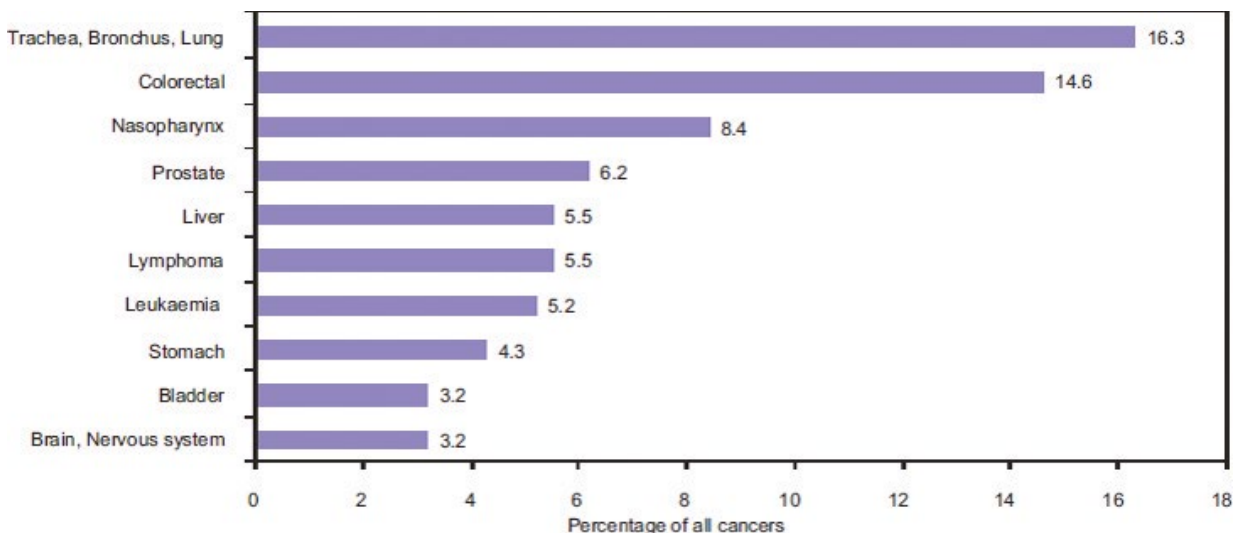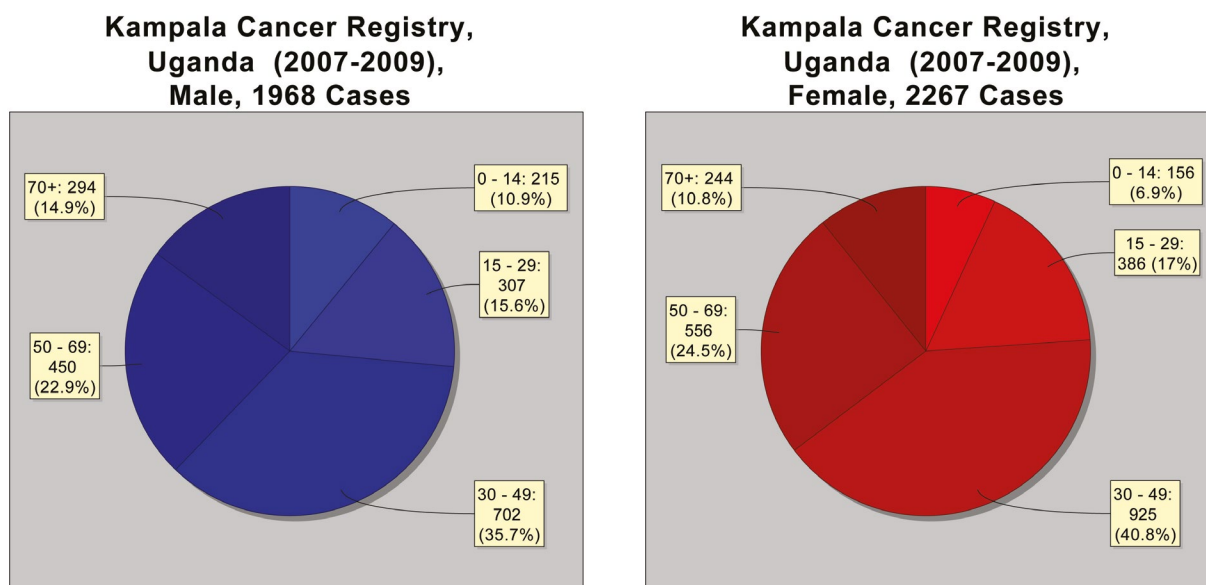

Cancer site	Percentage of all cancers
Trachea, Bronchus, Lung	16.3
Colorectal	14.6
Nasopharynx	8.4
Prostate	6.2
Liver	5.5
Lymphoma	5.5
Leukaemia	5.2
Stomach	4.3
Bladder	3.2
Brain, Nervous system	3.2

Fig. 6.3. Number of cases in 3-year period by age group and sex. Source: Kampala Cancer Registry Triennial Report, 2007–2009.

Kampala Cancer Registry, Uganda (2007-2009), Male, 1968 Cases

70+: 294 (14.9%)
0 - 14: 215 (10.9%)
15 - 29: 307 (15.6%)
50 - 69: 450 (22.9%)
30 - 49: 702 (35.7%)

Kampala Cancer Registry, Uganda (2007-2009), Female, 2267 Cases

70+: 244 (10.8%)
0 - 14: 156 (6.9%)
15 - 29: 386 (17%)
50 - 69: 556 (24.5%)
30 - 49: 925 (40.8%)

in presentation of cancer registry data include the following:

- *Bar graph or histogram*: commonly used for illustrations of frequencies, proportions, and percentages (e.g. Fig. 6.2).
- *Component band graph*: illustrates the size of components of the whole, using different colours, for example for different histologies (see Fig. 5.1).
- *Pie chart*: presents the contribution that different components make to the whole, commonly used to present the distribution of the most common cancer sites or age at incidence (e.g. Fig. 6.3).
- *Line graph*: commonly used to plot age-specific incidence rates or time trends (e.g. Fig. 6.4).

Examples of the recommended presentation of tables and graphs in cancer registry reports are also available in the African Cancer Registry Network model report at http://afcrn.org/resources/publica tions/115-model-registry-report.

2. Evaluation of the results

The aim of this section is to assist the reader in interpreting the results and to facilitate comparison with other registries. It should provide information on any changes in regis- tration procedures compared with the preceding period. The important elements in evaluating the results are consistency of the number of cases in each calendar year, site distribu- tion, and indices of quality of diagno- sis. The indices generally used are

Fig. 6.4. Age-specific incidence rates (black males). N.H.L., non-Hodgkin lymphoma. Source: Harare Cancer Registry Triennial Report, 2010–2012.
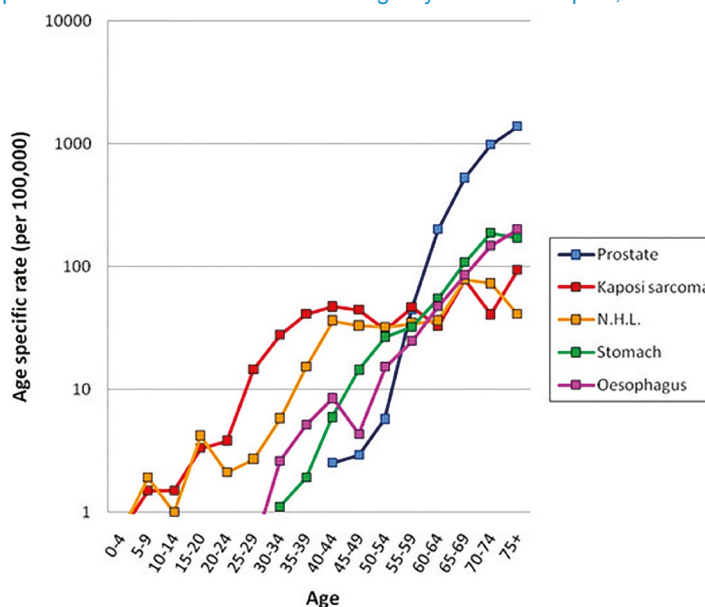
Table 6.1. Report checklist

Number	Recommended component
1	Executive summary of the report

Background information

2	Outline of the organization of the cancer registry
3	List of the professional staff
4	Description of the reporting procedures
5	Description of the sources of cases
6	List of reportable diseases
7	Description of coding procedures
8	Clear statement of definitions used in reporting
9	Population covered by registration
10	Reference for the population denominator data
11	Description of statistical terms and methods

Evaluation of findings

12	Consistency of the number of cases in each calendar year
13	Site distribution
14	Indices of validity of diagnosis
15	Demographic data
16	Differences compared with similar areas

Tabular presentation

17	Clearly defined contents of the table and the items
18	Denominator for rates
19	Frequency distribution in full
20	Rate or proportion, with the number of observations
21	Particulars and criteria of exclusions
22	Number of cases by site, age, and sex
23	Annual incidence rates by site, age, and sex
24	Age-standardized rates
25	Cumulative incidence rates
26	Tables for subsets of the population
27	Tables for indices of the validity of diagnoses

Graphical presentation

28	Limited amount of data per graph
29	Tabular information for the graphs must be presented
30	Appropriate choice of scale
31	Graphs should form self-contained units
32	Appropriate use of bar graphs, pie charts, and line graphs

the percentage of cases with morphological confirmation (MV%), the percentage of cases registered based on death certificate only (DCO%), and, if data on mortality are available, mortality-to-incidence ratio (M:I) (see Chapter 5 for definitions). These indices should also be presented by sex and site in the tabular section. Comparisons with other similar or neighbouring areas are also useful, as differences, such as lower incidence rates of major cancers, might point to under-reporting. A checklist of recommended components to be included in a cancer registry report is given in Table 6.1 (compiled from Jensen and Storm, 1991).

Upon publishing a report, it is advisable to assemble a stakeholders' committee to provide feedback to stakeholders, specific policy and research recommendations based on the results, and further plans and budgetary requirements. A response should also be provided to the data contributors, with the aim of improving quality and reporting. The pertinent media outlets should be briefed about the main findings.

Key points

- A key objective of a cancer registry is to produce statistics on the occurrence of cancer in a defined population.

- This information can be disseminated via cancer incidence reports, cancer registry websites, research articles, and press releases, and through direct communication with clinicians, health authorities, the media, or other data users.

- Even though cancer incidence does not vary markedly on an annual basis, most cancer registries are required by their stakeholders to publish new data annually. The cancer incidence report is the routine and baseline means of presenting registry data. These reports contain information on all reportable cancers and represent the main deliverable of a cancer registry, providing feedback to the stakeholders and the data providers.

- The main components of the report are background information, evaluation and presentation of the results, and the tabular section.

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