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
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-digit 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

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

**Fig. 6.2.** Ten most frequent cancers in males (percentages) in Malaysia in 2007. Source: Malaysia Cancer Registry Report, 2007.
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/publications/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 registration 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 distribution, and indices of quality of diagnosis. The indices generally used are
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### Key points

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