Completeness and timeliness: Cancer registries could/should improve their performance

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Abstract Cancer registries must provide complete and reliable incidence information with the shortest possible delay for use in studies such as comparability, clustering, cancer in the elderly and adequacy of cancer surveillance. Methods of varying complexity are available to registries for monitoring completeness and timeliness. We wished to know which methods are currently in use among cancer registries, and to compare the results of our findings to those of a survey carried out in 2006.
Methods: In the framework of the EUROCOURSE project, and to prepare cancer registries for participation in the ERA-net scheme, we launched a survey on the methods used to assess completeness, and also on the timeliness and methods of dissemination of results by registries. We sent the questionnaire to all general registries (GCRs) and specialised registries (SCRs) active in Europe and within the European Network of Cancer Registries (ENCR).

Results: With a response rate of 66% among GCRs and 59% among SCRs, we obtained data for analysis from 116 registries with a population coverage of ~280 million. The most common methods used were comparison of trends (79%) and mortality/incidence ratios (more than 60%). More complex methods were used less commonly: capture–recapture by 30%, flow method by 18% and death certificate notification (DCN) methods with the Ajiki formula by 9%.

The median latency for completion of ascertainment of incidence was 18 months. Additional time required for dissemination was of the order of 3–6 months, depending on the method: print or electronic. One fifth (21%) did not publish results for their own registry but only as a contribution to larger national or international data repositories and publications; this introduced a further delay in the availability of data.

Conclusions: Cancer registries should improve the practice of measuring their completeness regularly and should move from traditional to more quantitative methods. This could also have implications in the timeliness of data publication.

1. Introduction

The main goal of a population-based cancer registry is to continually collect data on all cancer cases occurring in the population resident in a defined area and to use the incidence data to provide information on risk. Incomplete ascertainment of cases greatly limits the value of the data, regardless of the amount of data collected on each case. Completeness of ascertainment – the extent to which all incident cases targeted by the registry (including subsequent cancers) are identified and included in registration – therefore remains the principal test of a cancer registry; beside accuracy in recording, classification and coding of diagnosis, complete ascertainment is crucial for providing accurate incidence rates, unbiased survival, and other statistics. Nowadays, when data collection is for many registries supported by the availability of a wide range of different sources, this task should be relatively easy. However, only thorough and painstaking monitoring, with precise and specific methodology, can provide assurance with documentation that this goal has been achieved. Incompleteness in case identification may not be uniform or consistent: for example, case finding is often more difficult in the very elderly, where multiple pathologies can make extracting information on cancer diagnosis from hospital records or death certificates more problematic [1].

Organisation of the health-care system can also affect the probability of a certain type of tumour being reported, resulting in variation in completeness of registration by cancer site. It is worth considering that incompleteness in case ascertainment may not only bias the incidence statistics, it will also affect survival and prevalence data, since not-ascertained cases are most probably not random but associated with a different probability of surviving when compared to ascertained cases [2]. The bias is even larger when associated with incomplete follow-up [3].

Several methods for assessing the completeness of registration have therefore been devised to detect whether, and how, cases may be missed; each of these methods addresses a particular aspect of the problem. Reviews of these methods can be found in Parkin and Bray [4,5] and Schmidtmann and Blettner [6], and are briefly summarised here.

Qualitative or semi-quantitative methods suggest a lack of completeness, compared to other registries, or over time, but do not actually quantify the number of missing cases. These are:

1. historic data/comparative methods [7]
   a. stability of incidence rates over time;
   b. comparison of incidence rates in different populations;
   c. shape of age-specific curves;
   d. incidence rates e.g. of childhood cancers.

2. mortality: incidence ratios [7]; log-linear variant [8]

3. number of sources/notifications per case [7]

4. microscopic verification of diagnosis [7].

Quantitative methods provide a numerical evaluation of the extent to which all eligible cases have been registered. These are:

1. independent case ascertainment [7];

2. capture–recapture methods [10–12];

3. death certificate methods:
   a. death certificate notification (DCN)/mortality:incidence (M:I) method [7,13];
   b. flow method [14–16].

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