Chapter 2: Techniques of registration

M.P. Curado

The quality of the cancer database in a cancer registry rests not only upon the quality of its sources of information but also upon the registration techniques adopted by the cancer registration team. If these techniques follow the international rules of cancer registration, populations may be compared with confidence. This chapter describes the variation between registries in the methods used to collect data on new cancer cases and on the population at risk in the geographical area covered by the cancer registry.

Registry background

The background of each cancer registry is relevant to the information it delivers. These definitions could affect the data, eventually resulting in an under- or over-reporting of cases. Each point of this issue is discussed briefly below.

Table 2.1 presents a definition of the area covered by the cancer registry. This includes its population, surface area, latitude, the year the registry started, the year population-based data became available, and whether cancer is reportable by L (Legislation), A (Administrative), N (Not reportable) or M (Mixed, a combination of the above). Other variables presented include the percentage of cases treated outside the registration area and the percentage of non-residents treated in the registration area. These topics are discussed in greater detail below.

Populations. The denominator used to calculate rates generally comes from official census data. Rates based on interpolations between censuses tend to be better than projections since the last census. The absolute size of the populations on which the rates are based affects the accuracy of the estimated rates. Rates based on small numbers are more subject to random variation than are rates based on large populations.

Surface area. The population density is calculated by each registry based on the population estimates from the surface area.

Latitude. This localises the position of the cancer registry and enables comparison within the same region.

Year registry started and Year population based data available. To get good-quality data in cancer incidence takes time. For instance, data from new cancer registries should be viewed with some caution, because in the first years of data collection the rates can be underestimated (due to over selectivity causing under collection) or overestimated (due to conflation with already-existing cases).

Cancer reportable. This is a tool used to get a better picture of completeness in cancer registration. The presence of laws and rules that make cancer diagnosis a reportable disease can ensure completeness of the registry data collection, especially in countries where the cancer registry is part of an integrated cancer control programme.

Percentage of cases treated outside the area. If the area covered by the population cancer registry has limited facilities for cancer diagnosis and care, such as surgery, radiotherapy, chemotherapy and pathology laboratories, it will be quite difficult for the cancer registry to get completeness in the area, as the residents with a suspicion of cancer will seek treatment outside the catchment area. Patients may also die outside the catchment area, or even return to die at home after having being diagnosed elsewhere, thus causing underestimation of the local incidence rates.

Percentage of non-residents treated inside the area. If the catchment area has a cancer care centre with a good reputation and treatment and diagnosis facilities available to the population, there may be an increased number of non-residents being treated in the same area as the resident cases. If these non-resident cancer cases are included in the cancer registry database, the local rates may be overestimated.

Case finding

If the geographical area covered by the cancer registry includes cancer centres and radiotherapy services, or any type of oncology or haematological treatment and diagnosis centres such as pathology laboratories where cases can be microscopically verified, this can improve data quality in cancer diagnosis, and is also an important source of quality data on local health services. The main sources of cases are described in Table 2.2.

Data Sources. These sources include hospital in-patient records, radiotherapy departments, public and private hospitals and their in- and out-patient facilities, pathology laboratories, autopsies, haematology laboratories, death certificates and screening programmes.

Abstraction and coding. This details the proportion of manual abstraction and coding of cancer information done by trained cancer registry personnel. Nowadays some cancer registries have automatic registration for which cancer registry personnel must verify the data quality and comparability.

Information recorded

Table 2.3 presents the information recorded by the population-based cancer registry. This is the most relevant information that should be collected by the cancer registries: Basic information includes name, sex, date of birth or age, and usual resident address (permanent) of each patient, which enables personal identification. Further information collected includes ID number; ethnic group/race/colour; incidence date, stage of disease; nature of the first treatment; brain and nervous system; follow–up for vital status (all/selected/none); death certificates used to update vital status; and active follow-up of the alive cases.

Basic information includes name, sex, date of birth or age, and permanent address of the patient. These items are essential for establishing the patient’s background in the cancer registry database, precluding double entry of the same case in the registry.

Incidence date includes the date of diagnosis or hospitalisation for first treatment, as well as if possible the primary site and histological type of the cancer diagnosed. It must be coded according to ICD-O-3 (see Chapter 3).

Date of birth is important to assist identification, particularly where there is limited variation in names, or when other specific identifying information is lacking. For comparability, it is necessary to convert any local dating system to a standard system used internationally.
ID number. Some countries have a number unique to the individual, and others have more than one. The use of these identification numbers varies, but whenever such a number exists, the cancer registry should promote its inclusion in the notification form of the cancer registry, as it can be used to eliminate double notification stemming from using multiple sources of information.

Ethnic group/race/colour. For some cancer registries this is an essential item, because social and cultural differences between groups may be related to the utilisation of medical facilities. It can be an indicator of differences in culture and habits that may determine exposure to carcinogenic factors. The definitions of the ethnic groups used by the cancer registries should be compatible with official definitions used for census reports.

Stage of disease can be identified when the diagnosis is made by the physician, and is a standard data point used to analyse post-diagnosis survival and disease stage. The final evaluation of survival depends upon the topography of the tumour at time of the diagnosis.

Nature of the first treatment. The type of treatment modality reflects the general access to basic treatment modalities (but it cannot be used to assess the efficacy of specific treatment).

Brain and nervous system identifies whether cancer registries include benign cancers of the brain and nervous system or not.

Follow-up for vital status, Death certificates used to update vital status, and Active follow-up of the living cases. The follow-up for vital status is important to evaluate survival after treatment and diagnosis, and it can be done actively through a phone call or visit, or passively by matching death certificates with incidence cases.

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Table 2.1 Registry background

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<th>Population</th>
<th>Surface area (km²)</th>
<th>Latitude</th>
<th>Year registry started</th>
<th>Year population-based data available</th>
<th>Cancer reportable by: L/A/N/M*</th>
<th>% cases treated outside registration area</th>
<th>% non-residents treated inside registration area</th>
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**Oceania**

| Australian Capital Territory | 315 652 | 2 400 | 35° S | 1971 | 1972 | L | NS | NS |
| Australia, New South Wales | 6 489 196 | 801 400 | 28° - 38° S | 1971 | 1972 | L | NS | NS |
| Australia, Northern Territory | 194 922 | 1 346 200 | 13° S | 1981 | 1991 | L | 0 | 5 |
| Australia, Queensland | 3 575 470 | 1 600 000 | 26° S | 1982 | 1982 | L | NS | 5 |
| South Australia | 1 504 567 | 984 375 | 26° - 38° S | 1977 | 1977 | L | NS | 6 |
| Australia, Tasmania | 472 195 | 68 114 | 42° S | 1978 | 1978 | L | 0.8 | 0.4 |
| Australia, Victoria | 4 763 103 | 227 420 | 37° S | 1940 | 1982 | L | < 1 | NI |
| Western Australia | 1 877 923 | NS | NS | 1981 | 1982 | L | NS | NS |
| French Polynesia | 232 782 | 4 000 | 7° - 29° S | 1981 | 1985 | L | NS | 0 |
| New Zealand | 3 853 350 | 270 534 | 39° S | 1948 | 1972 | L | 0 | < 1 |
| USA, Hawaii | 1 218 833 | 16 635 | 21° N | 1960 | 1960 | L | NS | 8-12 |

* L = legislation (a law exists)
A = administrative order (without a specific law)
N = not reportable
M = mixed (a combination of above)
NS, not stated
NI, not included
Table 2.2 Case finding, abstracting and coding

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<th>Hospital in-patient records</th>
<th>Radio-therapy depts.</th>
<th>Public hospital/clinic in-patient facilities</th>
<th>Pathology labs</th>
<th>Autopsy</th>
<th>Haematology labs</th>
<th>Death certificates</th>
<th>Screening programmes</th>
<th>% cases abstracted by registry personnel</th>
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**Oceania**

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