

# Planning and developing a population-based cancer registry

Establishing a new cancer registry requires collective agreement on the need for, or at the least the desirability of, the enterprise. As the cancer registry responds to the requirements of a community and its health system, the key players in cancer control should be involved in backing the progress and ensuring the sustainability of the registry. The success of the operation depends on the collaboration of clinicians, pathologists, and staff in administration in ensuring access to their data. There are many things to consider when planning a registry, as discussed in this chapter. But some components are absolutely essential (👉) or highly desirable (✔) in ensuring the success of the venture.

- In the institutional/professional domain:

- ✔ a director: the individual who will take professional responsibility for the registry, working together

- with other stakeholders and supervising the staff

- ✔ the medical specialists concerned with the diagnosis and treatment of cancer: pathologists and oncologists (radiation, medical, and surgical)
  - ✔ the directors of the major hospitals in the area served by the registry
  - ✔ departments dealing with registration of deaths in the area served by the registry.
- As part of the political/administrative framework:
  - ✔ the health department of national or local government concerned with planning and managing services for cancer treatment and prevention
  - ✔ inclusion of the cancer registry as part of the health information system of these departments.

At the outset, it is very important that all of the key stakeholders, who will be concerned with the registry as data providers or users, are aware of, and agree with, the concept of a PBCR, as it has been described in Chapters 1 and 2. Briefly:

- The cancer registry must collect information on *every* case of cancer identified within an agreed population (of a defined geographical area).
- Within the defined geographical area, the registry will be able to distinguish between residents of the area and those who have come from outside the area.
- The registry will register cases of cancer in residents treated outside the area.
- The registry must have sufficient information on each case to avoid registering the same case twice (which implies including personal information, including names).

- The registry must have access to all sources within the area where cancer patients are diagnosed and cared for.

The precise requirements for a cancer registry depend to a large extent on the local circumstances with respect to the level of development of medical services (diagnostic, therapeutic, and palliative) for cancer patients, the size and geographical dispersion of the population, and the resources – material and financial – available. Some basic principles were summarized in *Cancer Registration: Principles and Methods* (Jensen and Whelan, 1991; see Box 3.1).

## 1. The population

### 1.1 The population covered (“target population”)

The most basic decision to be made is to define the population covered by the registry: the “target” population in which cancer cases are occurring that the registry will enumerate. The issue of choosing a local or regional population, rather than the entire national population, for countries with a population of more than 4 or 5 million is an important issue to decide upon at the outset. The population covered by the registry may be the entire population of the country (or province), but more often it is just *part* of it – a “sample”, or one or more “sentinel sites” from which inferences (estimates) of what is going on in the whole population can be made.

The ideal solution to cancer surveillance might seem to be to develop a national PBCR with a catchment population comprising the entire country, yet in practice this is usually an unrealistic prospect. Either it is technically unfeasible, or the cost involved greatly outweighs the benefits

additional to those obtained from registration of a sample of the population.

In Fig. 3.1, the benefits of registration (and associated representativeness of the national profile) in support of cancer control and cancer research activities increase as registration coverage (and associated cost) increase. The benefits are immediate after the introduction of a regional PBCR, and ideally the registry area will be selected to ensure that statistics generated can be extrapolated beyond the confines of the catchment population. With further increments in coverage, the benefits increase only minimally. However, at the point of national coverage and heavy financial investment the benefits of registration are maximized, enabling, as an example, an assessment of health service performance by local geographical area.

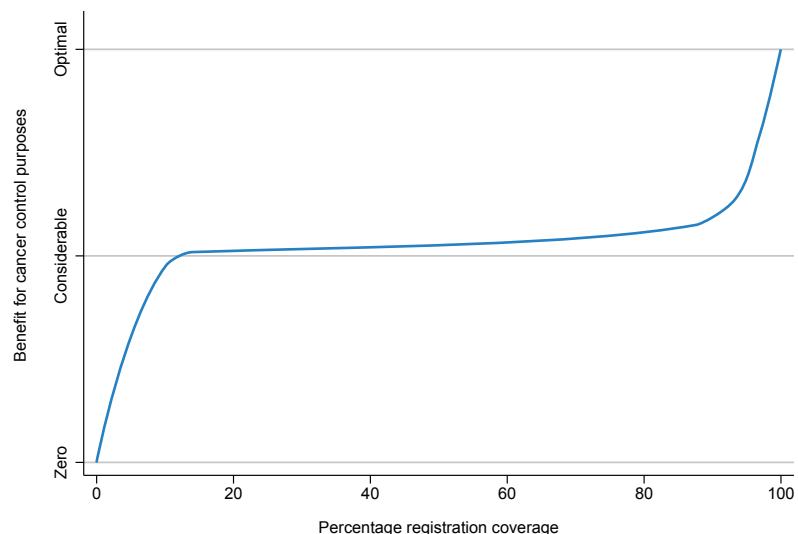
In summary, given the prohibitive costs involved, most of the requirements for planning and monitoring can be achieved through registration of a subset (sample) of the national population, using one or more regional PBCRs. The rolling out of a series

### Box 3.1. Requirements for a cancer registry.

Conditions necessary to develop a cancer registry include generally available medical care and ready access to medical facilities, so that the great majority of cancer cases will come into contact with the health care system at some point in their illness. There must also be a system for reporting clinical and pathological data, and reliable population data should be available. The cooperation of the medical community is vital to the successful functioning of a registry. Planning must allow for an adequate budget, since expenses tend to increase as time goes by, as well as the necessary personnel and equipment.

of PBCRs is becoming increasingly common in LMICs, as a means to have representative cancer data that account for the underlying inter-regional and urban–rural demographic and epidemiological differences.

Fig. 3.1. Benefits of increasing population coverage by cancer registration.



The choice of which local or regional population to register is dictated by practical considerations, rather than the ideal of an area (or areas) likely to be “representative” of the whole country. Thus, the area covered should have well-developed (by local standards) diagnostic and treatment services for cancer. Thus, it will attract cancer patients from outside the area (for diagnosis or care), and only few of its residents are likely to go outside the area for such services. For the cancer registry, it is very much easier to identify (and exclude from some calculations) non-residents diagnosed and treated in local hospitals than it is to try to find residents who have gone outside the area for their cancer care. Normally, then, the registry will be in an area where there are teaching hospitals, specialist oncology services, and pathology laboratories – that is, a major urban centre (usually including the capital city).

This major practical constraint on the choice of registration area will dictate the size of the population to be registered, as well as any theory as to what size is “ideal”. Thus, some cancer registries must cover much bigger populations than might be thought reasonable (the Mumbai Cancer Registry covers a population of about 13 million), while others might be very small, and so record rather few cases each year (the Seychelles National Registry covers a population of only 90 000; <http://afcrn.org/membership/members/96-seychelles>).

How much of the rural hinterland of the urban area to include depends upon the nature of the administrative divisions in the country, and on practical considerations, such as the size of the population and the distances involved. In any case, the registry area should conform to an administrative unit (city, district, province,

etc.) for which information on the size and composition of the population is available – the denominator for calculation of incidence rates.

### 1.2 Population denominators

“Population at risk” figures are used as denominators in the formulae for the calculation of incidence rates. The registry must have available estimates of the size of the population covered, by sex and 5-year age group, and, where there are important subgroups within the population (e.g. by race/ethnicity), for these strata also. Such data come from censuses, which are held at infrequent intervals (usually no more often than every 10 years). Between censuses, the population is estimated (intercensal estimates), as it is for the years following the most recent census (postcensal estimates). The latter are likely to be more speculative. Some of the issues involved in preparing such estimates have been described elsewhere (Pottier, 1992). However, the registry may find it preferable to rely on estimates prepared by official bodies, presumably staffed by appropriate experts, such as national or local government statistics offices.

It is important to remember that the accuracy of the incidence rates reported by the registry depends not only on the completeness and validity of the data it collects on cancer cases (see Chapter 5) but also on the accuracy of the “population at risk” data. Also, population estimates are likely to change over time; in particular, estimates that were based on postcensal projections often undergo quite drastic revisions when new census counts become available. This means that some published incidence rates will have to be revised in later publications.

## 2. Personnel

### 2.1 Director

In establishing the cancer registry, the most important element is the leadership of a motivated and respected director. A director will commonly (but not always) be medically trained, and will need to provide specialist advice on, for example, pathology, clinical oncology, epidemiology, and statistics (either personally or through colleagues).

### 2.2 Technical staff

Adequate staffing of the registry must be ensured from the outset and is dependent on the number of new cases expected annually, the data sources, and data collection procedures. In a large registry covering a population of several million, staff can be allocated to perform specific tasks, such as case finding and abstracting, coding and data entry, data analysis, software maintenance, and presentation of the results, whereas in a small registry the staff (sometimes only one person) will perform multiple functions. Staff skills are not limited to the technical aspects of registration but involve considerable personal and communication skills in liaising with staff and colleagues from medical institutions and other sources.

### 2.3 Training of staff

In particular in LMICs, the quality of the cancer registry data will be highly dependent on the qualifications of the registry staff and their technical competence. Cancer registration demands specific training, mostly on the job. Formal training courses and use of standard manuals for cancer registrars are recommended to avoid the establishment of individualized practices by single staff members,

as well as individualized practices by single registries deviating from standard procedures (see links below).

There are a few training resources for staff of registries in LMICs:

- The IARC–IACR *Manual for Cancer Registry Personnel* (Esteban *et al.*, 1995) is available from the IARC website (<http://www.iarc.fr/en/publications/pdfs-online/treport-pub/treport-pub10/index.php>).
- A useful training manual, *Pathology of Tumours for Cancer Registry Personnel* (Buemi, 2008), is available from the IACR website (<http://www.iacr.com.fr/PathologyManualApr08.pdf>). It explains in simple terms the genesis of tumours and the techniques used for pathological diagnosis, and contributes to the understanding of the terminology used.
- The Surveillance, Epidemiology, and End Results (SEER) Program of the USA provides many training materials, including some interactive training opportunities via the Internet (<http://seer.cancer.gov/>); however, these are not always well adapted to the circumstances of smaller registries in LMICs.

### 3. Physical location of the registry

The physical location of the cancer registry will generally be determined by its administrative dependency. The precise location, whether in a hospital department, university or research institute, government department, or the offices of a nongovernmental organization, is less important than its functional linkage with government health services and professional groups. In any case, the registry (generally through the director) should have the authority – administrative or professional – to be able to request and obtain detailed clinical information on cancer cases from medical services in the region. It is therefore advisable that the registry be linked

in some way with government health services (which may also facilitate access to official statistics databases, such as mortality and population data) and with professional groups. A location in a hospital (or pathology laboratory) might allow better access to clinical data and input from health professionals. Regardless of the location of the registry, it should maintain sufficient autonomy to facilitate cooperation with other health agencies and collaboration at both the national and international levels.

### 4. Equipment and office space

The office space required is obviously related to the size of the registry, in terms of number of staff and the need for storage of paper documents (registration forms, pathology reports, etc.). All registries now require computer equipment. Even the smallest registry needs a good-quality desktop computer, with an Internet connection, for running the registry management system (e.g. CanReg5; see Annex 1), as well as other standard software. The number of machines required is dependent on the size of the registry and the number of operators for data entry and analysis. Other essential equipment includes at least one printer/scanner/photocopier, as well as, depending on local electricity supplies, a voltage stabilizer or emergency power source.

### 5. Finance

The costs of cancer registration depend on the size and population of the registration area, the number and type of different data sources, the number of data items collected, and the data collection methods. These will determine the number of staff required and the costs incurred in data collection, which will be major budget items.

The United States Centers for Dis-

ease Control and Prevention (CDC) has collected cost data and conducted economic analysis and an evaluation of the National Cancer Registry Program (NCRP) in the USA (Tangka *et al.*, 2010). The true cost of operating cancer registries is unknown in LMICs, although the CDC has been validating a registry costing tool based on collaborations with several registries in Kenya, India, and Colombia. The aim is to aggregate cost for each registry activity based on staff salaries, consultancies, computers, travel, and training. The cost per case can then be calculated for core and advanced activities, and factors that affect cost can be further explored.

The elements that need to be considered when planning the budget for a cancer registry are shown in Box 3.2.

When planning a longer-term budget, it should be considered that the costs of the cancer registration process may increase over time as the registry expands its range of activities (e.g. to include follow-up of registered cases).

### 6. Legal aspects and confidentiality

It is advisable to ensure the legal basis for the operation of cancer registration in a given jurisdiction. Data confidentiality laws vary from country to country and should be taken into account when planning the cancer registry. In the setting of medical research, storage of medical data on identifiable individuals usually requires their informed consent. It is not possible for cancer registration to function under such a constraint. Cancer registries do not collect information from patients but rely on secondary sources, and thus asking for informed consent is impossible. Individual patients must be identifiable, at the very least to permit notifications of the same cancer from different sources, or different

### Box 3.2. Elements for planning the cancer registry budget.

#### 1. Capital costs (one-off)

- Office space and equipment/furnishings
- IT equipment (computers, printers, Internet link, etc.)

#### 2. Recurring costs

- Salaries
  - Direct: registry staff (full-time or part-time)
  - Indirect: allowances for part-time/contract work
- Running costs
  - Travel expenses (in particular for active data collection)
  - Rental/maintenance (including costs of water, electricity, etc.)
  - IT equipment maintenance/replacement
  - Consumables (office material)
  - Publishing reports and/or establishing and maintaining the registry website

#### 3. Training/workshops

Funding can be sought on an ad hoc basis once the registry is established.

time periods, to be linked in a single record. The value of a cancer registry in medical research is enormously enhanced if it can be used to identify cancers occurring in defined groups of subjects (cohorts), a procedure that also requires individual identification.

The cancer registry is an important tool in public health; without it, strategies for cancer control would be greatly hampered. A useful analogy is the notification of infectious diseases, which is so important in their control. As for infectious diseases, provision should be made for cancer to be a reportable disease. While this provides the necessary legal framework and may help with the number of cancer cases notified to the registry by clinical staff, mandatory reporting does not guarantee data quality or completeness of reporting. It does, however, provide some legal protection for data owners (hospital administrations, records officers, directors of private hospitals) who may be oth-

erwise concerned with the ethics, or legality, or permitting cancer registry staff access to the data they require.

Cancer registries have been concerned about the production of a code of confidentiality for the purpose of recording data on cancer. IARC–IACR have published *Guidelines on Confidentiality for Population-Based Cancer Registration* (available from the IACR website; <http://www.iacr.com.fr/confidentiality2004.pdf>). The basic principles of confidentiality are presented, as well as a set of measures from which a registry may select those appropriate for their local codes of practice. Although the publication is primarily adapted for European registries, it contains useful guidance for LMICs, for example on measures that the registry can use to safeguard confidential information, and on the development of guidelines and procedures for the release of registry data.

## 7. Advisory committee

The importance of involving all relevant stakeholders in planning a registry has already been emphasized. Their continued involvement in its operation should be ensured when establishing an advisory committee for the registry. The relevant stakeholders will vary according to local circumstances, but in any case, it is important that the advisory committee consist of members from the public health, clinical, and academic communities, as the major users of the cancer registry data. Cooperation and involvement of clinicians, as the main providers of cancer registry data, is particularly important. If other groups such as cancer societies, hospice care services, and patient associations operate within the registration area, representatives of these stakeholders should be involved as well.

The role of the advisory committee is to oversee the activities of the registry, including formulating policies for staff recruitment and training, reviewing the results of the registry and ensuring that they are available to decision-makers as well as researchers, and helping to solve operational problems. The committee members may also provide assistance and contacts in efforts to attract funding to sustain or further develop activities at the registry. The committee may wish to establish subgroups, to deal with, for example, written requests for access to registry data. Working closely with the responsible programme owners in developing the registry programme and enquiring as to their needs can also be important in gaining funding support and obtaining local “buy-in” in the use of the data for cancer control.

## Key points

- Given the prohibitive costs involved, most of the requirements for planning and monitoring can be achieved through registration of a subset (sample) of the national population, using one regional PBCR or a series of regional PBCRs.
- At the outset, it is very important that all of the key stakeholders, who will be concerned with the registry as data providers or users, are aware of, and agree with, the concept of a PBCR.
- The key players in cancer control should be involved in backing the progress and ensuring the sustainability of the registry. Success depends on the collaboration of clinicians, pathologists, and staff in administration in ensuring access to their data.
- The cancer registry must collect information on every case of cancer identified within a defined geographical area and be able to distinguish between residents of the area and those who have come from outside the area.
- In planning a PBCR, there are many things to consider, including the definition of the population, the necessary personnel, the physical location of the registry, the equipment and office space required, adequate financing, ensuring that legal aspects and confidentiality are dealt with, and – last but not least – the appointment of an advisory committee to oversee the activities of the registry.