Chapter 4. Planning a cancer registry

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Reasons for establishing a cancer registry

The world population is approaching 4500 million, with some three quarters of this total living in the developing countries. The number of cancer deaths worldwide has been calculated to be approximately 4 million each year (Muir & Nectoux, 1982), and an estimated 6.35 million new cases of cancer occurred in 1980, corresponding to an overall incidence rate of 143 per 100 000 per year (Parkin *et al.*, 1988a).

At both the national and community level, cancer registration schemes are central to research into the nature and causation of cancer, to the planning of health service resources and cancer control programmes, and to the assessment of their efficacy (see Chapter 3). Cancer registration is thus part of a modern health information system.

Other sources of data available to measure levels of cancer in a community include hospital registry data (see Chapter 13) as well as special patient series based on, for example, pathology records and autopsies. While interesting information on cancer patterns has been derived from such data collections, they are necessarily incomplete and may represent a selective and biased sample of the patient population (Parkin, 1986). An accurate picture of the cancer burden depends on the creation of a population-based cancer registry.

The role of the cancer registry in developing countries must not be underestimated. Many developing countries have very young populations, with over 40% of the total under 15 years old and less than 5% aged 65 years or more. Cancer has, in the past, been neglected as a cause of death and disability. However, with increasing numbers of elderly people, and declining relative importance of infectious diseases, this situation is likely to change. The cancer registry represents an effective and relatively economic method of providing information for the planning of cancer control measures. Chapter 14 examines some of the particular problems faced by cancer registries in developing countries.

Definitions

Cancer registration may be defined as the process of continuing, systematic collection of data on the occurrence and characteristics of reportable neoplasms with the purpose of helping to assess and control the impact of malignancies on the community. The *cancer registry* is the office or institution which attempts to collect, store, analyse and interpret data on persons with cancer. The synonym 'tumour registry' is often used, in particular in the United States of America, and this term may often be more appropriate, since most cancer registries include the registration of a number of benign tumours or conditions, e.g., urinary tract papillomas and brain tumours (see Chapter 7). The term *cancer register* denotes the file or index in which the cancer registry holds its tumour cases.

Although the means of recording cases may to a large extent be identical, a distinction must be made between the population-based cancer registry and the hospital registry. The *population-based cancer registry* records all new cases in a defined population (most frequently a geographical area) with the emphasis on epidemiology and public health. The *hospital-based cancer registry* records all cases in a given hospital, usually without knowledge of the background population; the emphasis is on clinical care and hospital administration. The hospital registry may form the nucleus for a population-based cancer registration scheme.

Planning a population-based cancer registry

It is essential that the purposes of cancer registration be clearly defined before a registry is established: priorities for individual registries have to be decided in the context of the medical facilities already existing and of particular local needs. The population-based cancer registry must collect information on every case of cancer identified within a specified population over a given period of time. This implies that the registry will operate within a defined geographical area, be able to distinguish between residents of the area and those who have come from outside, register cases of cancer in residents treated outside the area, have sufficient information on each case to avoid registering the same case twice, and have access to an adequate number of sources within the area.

The way in which a registry operates depends, inevitably, on local conditions and on the material resources available. 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.

Advisory committee

It is important from the beginning to seek the cooperation and support of the medical community. The registry may depend on doctors for case notifications, and even when doctors do not notify cases themselves their cooperation is essential, since the registry must then abstract information on named individuals from clinical documents (see Chapter 5). The plans for a cancer registry should be discussed with members of the medical profession, medical agencies and health care officials. It is particularly helpful to set up an advisory committee, representing sponsors, sources of information on cancer cases (Chapter 5), and potential users of the registry's data (Chapter 3).

Membership of such a committee will vary from country to country. Organizations which may sponsor a cancer registry include health departments, cancer societies, medical schools and universities, health insurance companies and cancer institutes. Sources of information could comprise a medical association or society, hospital administration, specialized services such as pathology and clinical oncology, a death registry and a government census department. Users of the registry data could include clinical oncologists and epidemiologists. This committee should be maintained when the registry is established to ensure the close contact with the medical and public health environment which can facilitate access to the data sources.

Population denominators

In the planning of a population-based cancer registry, the availability of accurate and regularly published population data must be investigated. Population figures by sex and five-year age group are required for the registration area and for any subdivisions which the registry might wish to examine. In countries where it is not possible to monitor internal and external migration, estimates of population for intercensal years may be imprecise.

The cancer registry must use the definitions of population groups, geographical areas etc. exactly as they are presented in the official vital statistics.

Legal aspects and confidentiality

Reporting of cancer cases to a registry may be voluntary, or compulsory by legislation or administrative order. The legal aspects of cancer registration must be considered when planning a registry: in many countries it is necessary to ensure a legal basis for the registry and to consider the protection of individual privacy. It is paramount that the issue of confidentiality be taken into account. These questions are treated in detail in Chapter 15.

Size of population and number of cases

No firm recommendations can be given on the optimal size of the population covered by the cancer registry. In practice, however, most cancer registries operate with a source population of between one and five million. With larger populations it may be difficult to maintain completeness or quality of the data; with smaller populations it takes longer to obtain meaningful figures. There are, however, registries operating within larger and smaller populations, e.g., in the former German Democratic Republic with 17 million inhabitants and in Iceland with 200 000.

In countries with large populations, autonomous but linked regional registries may be more effective, e.g., England and Wales. In smaller countries such as Denmark, which has the added advantages of excellent linkage with vital statistics information and a population in which every individual has a unique identification number, good quality national registration is feasible. For countries in which national coverage is difficult to achieve, it is preferable to set up smaller registries in representative areas, as is done in the United States of America (SEER Program) and in the Indian Council of Medical Research cancer registry network (Indian Council of Medical Research, 1987).

Physical location of the registry

Where a registry is situated will depend on local factors: registries have been established in a variety of locations such as universities and associated hospitals, bureaux for health statistics, and institutes of pathology.

The physical location of the cancer registry is often intimately linked to the administrative dependency of the registry. In order to operate effectively, the registry must have sufficient standing to be able to request and obtain detailed demographic and medical information from medical services in the region. It is, therefore, advisable that the registry be linked in some way with governmental health services (if they exist) or with professional groups. Some cancer registries are set up and administered by voluntary agencies, such as a cancer society. Whatever the administrative background, experience shows that the cancer registry should be as autonomous as possible, since this will best fulfil its needs as an ever-growing organization, and facilitate cooperation with other health agencies and the establishment of direct contacts at both the national and international levels.

Finance

The size of the registration area, the number of data items collected, the number and type of the different sources of data, and whether or not the registry carries out regular follow-up of registered cases, will all affect the amount of funding required. In the USA, the SEER Program, which has a system of active registration with trained registry staff extracting hospital records and annual follow-up of cases, costs were estimated to be US $100 per case (Muir *et al.*, 1985). In contrast, a small registry in Africa, employing one or two staff to search for 500–2000 cancer patients and recording few variables on each case, may operate for a few thousand dollars a year. In the Doubs department of France, with a population of 477 671 and 1528 new cases per year, the funds needed for cancer registration are approximately equal to the cost of treating three lung cancer patients.

The one fact which is certain is that costs of the registration process will increase over time: even when the annual number of new cases to be registered stabilizes, there will be a greater load of cases to be followed for registries doing active follow-up. Additional resources in terms of staff, equipment and space will be required as the size of the data-base increases, and work commences on analysis and publication of results. Financing for specific research projects can be sought on an *ad hoc* basis once the registry is established.

Personnel

The single most important element in any cancer registry is the leadership of a director dedicated to its success. The director will require the support of other personnel.

Numbers

Staff are needed to collect the data, to code and collate the information (e.g., checking for duplicates, completeness and consistency), and to analyse and present the results.

Adequate staffing of the registry must be ensured from the outset. This is an aspect of the cancer registration process which experience has shown tends to be underestimated. Since cancer registration methodology can only be learned at a cancer registry, provision has to be made for training and equipping the full complement of personnel as the registry develops.

As with finance, the level and quantity of staff required depend to a great extent on the size of the population covered and the number of new cases diagnosed annually, as well as the choice of information to be collected, the methods used for case finding, and the recording, coding and data management practices adopted (see Chapters 5–9). For example, whilst some registries rely on spontaneous notifications, usually given in a summary on the registry notification form, which may be accompanied by copies of clinical notes and/or pathology and other reports, others use their own staff to visit hospitals in order to find cases and abstract information. Descriptions of four cancer registries with very different methods of working are given in Appendix 3. The Thames registry employs peripatetic field staff who visit large hospitals on several days a week, while smaller hospitals are visited at a frequency which depends on their cancer case load. The registry of Cali, Colombia, receives case reports routinely from the major hospitals and pathology laboratories, and from the X-ray, haematology and radiotherapy departments, mainly through the secretarial and clerical staff. However, once a year a field survey of all sources of cases (including private physicians) is made by a group of medical students given special training for the work. New York State, USA, relies primarily on the hospital cancer registries of the larger hospitals for notifications. In order to improve the quality of the reports submitted to the registry, three-day workshops are organized annually for hospital tumour registrars.

Each system thus involves differing requirements in the number and type of registry personnel, and it may be very difficult to generalize. Nonetheless, in a survey of 61 cancer registries which supplied data for Volume IV of the monograph series *Cancer Incidence in Five Continents*, it was found that one staff member was necessary for each 1000 or so new cases occurring annually in the population covered by the registry (Menck & Parkin, 1986).

Qualifications

The staff of a registry consists of persons with professional and technical training and experience. In many places it is considered that the registry director should be medically qualified, with a background and interest in epidemiology or public health, and some knowledge of oncology. Depending on the size of the registry, it should be staffed with or have access to the advice of consultants on pathology, clinical oncology, epidemiology, public health, data-processing and statistics.

The technical staff comprise the record clerks, responsible for case-finding and abstracting, and statistical clerks, concerned with coding patient information and processing tumour records. The specific expertise required in the registry can be acquired on the job or by means of a specific training course. Data-processing experts and programmers must be associated with the registry from the beginning in order to plan and implement data storage and retrieval (see Chapter 8).

Finally, office staff such as typists and administrators will be needed, again depending on the size of the registry.

Training

Training of the registry personnel at all levels is an important aspect of the cancer registry's operations. The work in a cancer registry is repetitive and at the same time demands great concentration. It demands specific training, mostly on the job, for all types of personnel. Formal, continued training courses are recommended for all registries in order to avoid the establishment of individualized practices by single staff members. Similarly, it is important that personnel performing the same type of duties in the registry have adequate time for discussion, for example, of the abstracting and coding practices. Provision should be made for training courses in hospitals if self-reporting systems are used. Instruction manuals for tumour registrars are essential, such as those issued by the SEER program in the USA (Shambaugh *et al.*, 1980a,b, 1985, 1986a,b; Shambaugh & Weiss 1986), or by IARC/IACR for cancer registry personnel, particularly in developing countries (Esteban *et al.*, 1991) and for cancer registry personnel in Canada (Miller, 1988).

Training of the registry staff on a continued basis gives greater job satisfaction and makes it easier to keep personnel—the resignation of experienced staff members usually represents a severe loss. It is important to do everything possible to explain the aims and purposes of cancer registration to the staff and to emphasize their important role in the registry operations.

Equipment and office space

In common with every other aspect of planning a cancer registry, the equipment and space required will depend on the size and functions of the registry. While a registry can often be initiated in a small space and with little equipment, it is wise to anticipate probable future requirements.

Apart from normal office equipment, the basic requisite is storage space and secure, lockable storage facilities for the case documents. Even when microfilming is adopted as a space-saving measure, the problem of storage will come up at some stage of the registry's existence. A manually operated registry will also need a considerable amount of space for filing cabinets.

The computer facilities chosen by a registry will depend, again, on size and local conditions. Many smaller registries are now starting operations with a microcomputer; other new registries are using locally available facilities in a hospital or university. Chapter 8 discusses the operations in manual and computerized registries, and a microcomputer-based system for developing countries is described in Appendix 4. Information about the range of computer facilities used in cancer registries is given in the publication *Directory of Computer Systems used in Cancer Registries* (Menck & Parkin, 1986).

Conclusion

The importance of registration in a comprehensive cancer control programme should be stressed when putting the case for starting a registry. The registry's success will depend on the cooperation of the medical profession, and it is worth putting time and effort into establishing and maintaining relations with the local medical community. At the same time it must be borne in mind that a cancer registry is a long-term operation: the first valid results cannot necessarily be anticipated for several years after beginning operations. By its nature, the registry will expand and require increasing material support as time goes by. It is therefore vital to ensure that the administrative and financial plans make provision for expansion, both as a result of the increasing number of cases in the register and the increasing possibilities for using the data.