

## Chapter 14. Cancer registration in developing countries

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At first sight, it may seem that cancer registration is a luxury that ought to occupy a lowly place in the priorities of the health services of a developing country, given the many competing demands upon usually slender financial resources. Yet this would be a mistaken belief, firstly because cancer is already a significant health problem in the developing countries of the world, and one that is likely to increase in future, and secondly because the presence of an adequate information system is an essential part of any cancer control strategy.

At present, half of the new cancer cases in the world occur in the developing countries (Parkin *et al.*, 1988a). The young age structure of these countries means that the overall (crude) incidence rates appear to be low, even though age-specific risk may be little different from that in the developed world. The young age of the population does mean, though, that much of the burden falls upon individuals in the active age range of 25–64, with a correspondingly great impact upon family life. Furthermore, the sheer size of the problem is bound to increase, given the rapid increase in population of many countries and, with control of infectious disease and curtailment of family size, an increase in the proportions of the elderly.

The uses of morbidity data may be summarized as follows (WHO, 1979):

(1) They describe the extent and nature of the cancer load in the community and thus assist in decision-making and the establishment of priorities.

(2) They usually provide more comprehensive and more accurate and clinically relevant information on patient characteristics than can be obtained from mortality data, and they are therefore essential for basic research.

(3) They serve as a starting-point for etiological studies and thus play a crucial role in cancer prevention.

(4) They can be used for assessing the overall effect of efforts to improve the survival experience of cancer patients.

(5) They are needed for the monitoring and evaluation of cancer activities.

Some of these functions can be fulfilled by mortality data derived from vital statistics systems. However, interpretation of mortality data is never straightforward

(Muir & Parkin, 1985), and few developing countries have in place comprehensive systems for the registration, coding and analysis of statistics on cause of death. In such circumstances, the cancer registry provides a relatively cheap method of planning and evaluation of cancer control activities, as well as providing a focus for research into etiology and prevention (Olweny, 1985).

### *Types of registry*

Ideally, the objective should be to establish a population-based cancer registry, so that the incidence rates of different tumours can be calculated, and so that the data generated are an accurate reflection of the cancer picture in the community. The establishment and maintenance of population-based registries will form the subject matter of this chapter. However, because of the relative ease with which they can be founded, cancer registries in developing countries often start on the basis of cases attending one (or several) hospital(s), or of cases of cancer diagnosed in a department of histopathology.

The hospital-based cancer registry and its uses are discussed in Chapter 13. In developing countries, it may be little more than an extension of the medical records department, or may be limited to cases attending specialized institutions with radiotherapy or chemotherapy facilities. Although there are considerable advantages in the relative ease with which data can be collected, and in the range and completeness of this information, there is a price to be paid, particularly in the incomplete and biased picture of the cancer situation which is given by such registries. The same is true of registries based on histopathological diagnoses—here the information about the tumour itself is of high quality, but demographic data about the patient may be rather sparse, and the cancer pattern which emerges is heavily biased by the over-representation of easily accessible tumours. Having said this, the information which hospital-based or pathology-based registries can provide can yield very useful insights about the relative importance of different cancers, providing the material is interpreted with due care as to its inherent biases (Parkin, 1986). When these registries cover entire national populations, it may be possible to study the risk of cancers in different population subgroups (e.g., different regions or ethnic groups) by using proportional methods (see Chapter 11), since the ascertainment bias for different tumours might reasonably be assumed to be similar for the subgroups concerned.

In some developing countries, hospitals in large cities provide comprehensive treatment and care exclusively for cancer patients. Registries in such hospitals have reasonably uniform clinical information on extent of disease and treatment. If a social service department exists in the hospital, follow-up records might be quite good and the registry can provide survival data on one or more cancer sites. Such data are valuable in clinical research, and can serve as a basis for planning and evaluating therapeutic services.

Nevertheless it should be the aim, whenever possible, to develop hospital- or pathology-based registries into population-based registries. The extra difficulties and expense involved are certainly outweighed by the enhanced validity and usefulness of the data generated. It is a reasonable target for all but the smallest countries to

establish at least one population-based cancer registry. Larger countries, with varying ecological and ethnic structure will clearly need several regional registries to reflect the corresponding differences in cancer occurrence.

### *Problems of cancer registration in developing countries*

The problems involved in collecting and analysing cancer registry data in developing countries have been summarized by Olweny (1985) and by WHO (1979).

#### **Lack of basic health services**

In developing countries, facilities for the diagnosis and treatment of cancer cases may be particularly scanty. They will generally be concentrated in the major towns or cities, despite the fact that the majority of the population is rural. The cancer registry will have to be established in such centres, since these are where cases will go for treatment. This has the obvious disadvantage that the population studied will not be representative of the country as a whole. It is probably true that urban populations will make greater use of hospitals, clinics and general practitioners than their rural counterparts. In some societies, large numbers of individuals may seek treatment from practitioners of traditional healing systems, so that they could not possibly be enumerated by cancer registries (unless, as often seems to be the case, they resort to western medicine at a very late, incurable stage of the disease).

Even in the major cities, the hospitals and clinics which exist may be perpetually overcrowded. Although doctors, nurses or clerical staff may not be asked to notify cases themselves (see below), registry staff will frequently have to ask them to clarify incomplete or apparently contradictory information. Busy health care workers may not be sympathetic to helping with tasks which they regard as irrelevant to patient care.

The lack of hospital facilities for the diagnosis and treatment of cancer patients greatly impedes accurate cancer registration. Firstly, the quality of diagnostic information may be poor, and based on clinical examination only. Secondly, patients with advanced tumours, or those for which no treatment is available may not be admitted to hospital at all, so that records of their existence are scanty or inaccessible (in outpatient clinics or consulting rooms). Post-mortem examinations are generally few in number.

#### **Lack of stability of the population**

The populations of developing countries are generally more mobile than those of the developed world. This applies not only to traditionally nomadic societies, but also to the increasing tendency of rural populations to migrate, often temporarily, to towns and cities in search of employment or higher living standards. Other communities are forced to move because of social, political and economic upheavals. These population movements are often unrecorded—they invalidate census data on populations at risk of cancer and greatly complicate the definition of residents for population-based cancer registries. This is a particular problem with the rapidly expanding populations of the large cities of developing countries.

**Identity of individuals**

The essential feature of a cancer registry is its ability to distinguish individuals from events (admissions, biopsies). Avoiding duplicate registrations requires a comprehensive and reproducible method of identifying individuals. Where a system of identity numbers is widely used (for example, in Scandinavia or Singapore), it is a useful way of linking together the records of a single individual. However, the most universal and generally used personal identifier is the name. The utility of using names will vary depending on local custom. Sometimes surname (or family name) is not used—persons are known by their given name plus the father's or mother's name. Sometimes family names in a particular area are quite few, and almost useless as personal identifiers. Individuals may change names at will—for example those giving birth to twins may acquire new and prestigious titles. Variations in spelling of names is quite a frequent problem, particularly if a large percentage of the population is illiterate. This problem is greatly compounded if transliteration from the local to the Roman alphabet is undertaken (perhaps to allow the use of commercial computer software). In such circumstances, it is very easy for the same individual to be registered as a new case of cancer on two or more occasions.

**Lack of trained personnel**

A major problem in establishing and maintaining a cancer registry is the lack of appropriately and adequately trained personnel. This may affect the registry directly, in that it is hard to recruit people to act as data collectors, coders and analysts without the need for them to be sent for training elsewhere. This will often be in cancer registries in developed countries, where the experience gained may be inappropriate in several respects. For example, in developed countries, cancer registries implicitly rely upon the presence elsewhere in the health care system of secretaries, records clerks and information officers who are trained in the recording and maintenance of files containing accurate information on patients. Such individuals are far fewer in number in developing countries, and may be overwhelmed with the task of trying to maintain a medical records system, and to produce regular statistical reports, in circumstances which are quite inadequate to the task. The cancer registry may thus be obliged to rely upon more primary sources of information, such as medical or nursing records, or operation books, a method which is generally rather inefficient in terms of quantity and quality of information collected in relation to the time involved.

**Lack of follow-up**

Follow-up data on cancer patients are useful as a check on the accuracy of the original diagnosis—the information recorded by the registry should be updated as new facts come to light. It is also necessary to evaluate outcome of care, and to compute survival rates (see Chapter 12); these are of particular interest to clinical staff, upon whose cooperation the registry depends. Obtaining follow-up data is usually very difficult in developing countries. Few hospitals have the facilities available to spare for appointments for patients who may have no complaints. In any case, most patients do

not appreciate the need for follow-up, and, even if they did, would be inhibited by the costs involved. There are also problems of a more practical nature such as unreliable postal services, unstable addresses and a mobile populace. These problems may be lessened when a cancer hospital has a social service department to assist patients, and in some countries concessionary fares on public transport are available for patients and attendants to visit the hospital.

### **Non-availability of census data**

Population-based registries require information on the size and nature of the population served by the registry, information which ultimately requires the availability of census data. Censuses are particularly difficult to conduct in developing countries (for many of the reasons that registration is difficult), and so tend to be infrequent, and the results available late, in inadequate detail, or only at a high financial cost. Occasionally, census results may be suppressed for political motives.

### **Lack of data-processing facilities**

Almost all modern cancer registries have access to a computer, which is of enormous help in recording, filing, checking, sorting and analysing data. Because of lack of funds and trained personnel, registries in developing countries may be obliged to start up using manual card-filing systems. The capabilities of manual systems should not be underestimated—many of the data from the early decades of cancer registration were obtained with such systems. However, manual systems inevitably require more trained manpower to maintain, and processing and analysis of data are slower, causing serious delays in the feed-back of information to programme managers and research workers, thus affecting adversely the value of the information.

### **Confidentiality**

The application of rigid rules to prevent transmission of named data to cancer registries can cripple their function (see Chapter 15). To date, there has been little emphasis on legislation concerning confidentiality of data in developing countries, who perceive (rightly or wrongly) other issues to be more pressing or relevant. This situation may, however, change.

### ***Establishing a cancer registry***

Cancer registration must be adapted to available resources, and registration that is too ambitious is unlikely to succeed and to be maintained. External assistance has often led to the setting-up of sophisticated systems copied from affluent countries, which cannot be continued when the assistance ceases. Much can be achieved with simple cancer registration, and the emphasis should be on the quality of a limited amount of information.

It is wrong to assume that complicated techniques are essential in cancer registration: what matters is the quality of information, the coverage and the

adequacy of the reference population. These are the factors that lead to the best possible estimates of incidence and these can be achieved by relatively simple schemes.

### **The area covered**

There is usually little choice, since the area will contain the major treatment facilities for cancer, so that health care and statistical personnel are present and can be involved, and so that the area attracts persons for treatment. It is much easier to operate a registry in an area where outsiders come for treatment (they can be excluded from registration, or from analysis of results) than where a significant percentage of the populace is being treated elsewhere. The latter circumstance means that appeals have to be made to hospitals elsewhere for help (rarely completely successful), or registry staff have to travel long distances to track down medical records.

The registry area should be defined in terms of administrative boundaries which can be matched both with the address of the patients and with available information on the size of the population at risk (usually from the census).

### **The registry committee**

The role of the cancer registry committee has been discussed in Chapter 4. Establishing such a committee is useful in the planning stage in order to facilitate establishment of a registry; later, its function is mainly to help ensure the collaboration of all the necessary individuals and departments upon whom the registry depends. The committee may include representatives of health departments, universities and cancer societies (particularly if any of these provide funding), as well as representatives of the various departments acting as data sources.

### **Personnel**

Undoubtedly, the major key to success of a cancer registry is the presence of an individual in the position of director or supervisor who is enthusiastic and highly motivated to establish and maintain a registry. Such individuals have, in the past, generally been medically qualified, and have had an interest in cancer statistics or epidemiology. Without appropriate supervision, the impetus needed for the meticulous and demanding work of a registry can rarely be maintained.

The number and type of staff required to undertake the tasks of case-finding and recording vary enormously, depending on the methods of data collection, and degree of automation. Only careful pilot work at the planning stage can establish this; it is, however, easy to underestimate the number of clerks required to visit hospital departments, laboratories etc. to search for cases. Individuals with a wide diversity of backgrounds have made excellent registry staff: medical secretaries, record clerks, nurses, health inspectors, other paramedical personnel, laboratory technicians etc. Medical students have been widely used for case-finding in South America. The choice will depend on local circumstances and availability of funds.

Training of registry personnel is a perpetual problem for developing countries.

Senior staff should certainly spend some time in cancer registries elsewhere, but obtaining suitable training for junior staff is difficult. The regional offices of WHO or the IARC can offer advice and sometimes practical help. A training manual for registry staff in developing countries is currently under preparation at the cancer registry of Rizal province in the Philippines (Esteban *et al.*, 1991).

### **Funding**

Obtaining funds is often the most difficult task of all—but a registry should have access to suitable finances for three to five years before commencing operations. Funds are needed for staff salaries, for expenses (e.g., for travelling), for fixed assets (particularly a suitable microcomputer), and for consumables such as stationery.

Sources of funds include government departments (national ministries or local health departments), universities and voluntary agencies (e.g., cancer societies). Research funds may be available from external sources, but this solution is rarely to be relied upon in the long term; in India, however, the Council of Medical Research has provided support to a network of cancer registries for several years.

### *Methods of registration: sources of data*

Except in most unusual circumstances, it will be necessary to adopt active case-finding methods (see Chapter 5). Passive registration, which relies upon notification of cases by others, will not be a success, given the other pressures on health care staff and the fact that the registry is not actually very relevant to them personally, serving as it does a wider function in public health prevention and research. It is sometimes felt that a legal requirement to notify cases might remedy this reluctance. This is not true—the presence or absence of statutory notification requirements bears no relation to the completeness of registration. This is not surprising, as it is hardly practicable, or even desirable, to take legal action against health care personnel for not completing a form!

Active registration means that the registry staff themselves have to collect data on cases of cancer coming into contact with health services in every possible way. These have been described in Chapter 5. The most relevant in developing countries will be the following.

(1) Departments of pathology: cases histologically or cytologically diagnosed. These will include cases diagnosed by biopsy, cytology or at autopsy. Unfortunately, although the quality of diagnostic data is very good, the patient identifying data (e.g., date of birth, address etc.) are not. This is because the pathology department must rely upon some type of request form for such data; these are filled in, almost invariably rather poorly, by busy clinicians who are averse to supplying data which may not be to hand (e.g., in the operating room), and which they feel are irrelevant.

(2) Departments of radiotherapy/oncology: cases treated. These departments treat practically only cancer cases. They almost always have good records.

(3) Other hospital departments. Medical records departments, if these are adequate, may be able to provide abstract sheets or case records of cases of cancer

treated in the hospital. If so, this avoids the need to visit individual services. However, it is usually necessary to check that there is not too much loss of information, or failure to register cases.

(4) Other laboratory services. If chemical pathology services are separate from histopathology services, they may have information on cases diagnosed by assays such as alpha-fetoprotein, acid phosphatase, chorionic gonadotrophin etc. The diagnosis of leukaemia from smears of peripheral blood or from marrow aspirates may be the responsibility of the haematology department, and so may be unknown to the pathologist.

(5) Outpatient clinics. Elderly patients, or those with advanced or untreatable tumours may never pass beyond the outpatient department. It is important to include them in the registry, even though the diagnosis may be based on clinical examination alone. Unfortunately, the records of outpatient clinics are generally very sketchy. They may be little more than ledgers maintained by the nursing staff with a list of patient names (with age and sex) and presumptive diagnoses. Medical staff may not always be helpful in ensuring that the latter are updated after the consultation.

(6) Private clinics and diagnostic laboratories. It is important to include these. The level of cooperation given to the registry is variable, and it is here, if at all, that issues of confidentiality tend to be raised by those responsible. Where a significant proportion of cancer cases is treated in one private institution (or use one private laboratory), a representative from it might, with advantage, be included on the registry committee.

(7) Death certificates. The quality and comprehensiveness of certification of cause of death in developing countries is very variable (Muir & Parkin, 1985). Nevertheless, it is usual for some form of certification to exist, particularly in urban areas and, unless it is carried out by non-medical personnel, it provides a useful source of data. An attempt should be made to find out why a case has come to the notice of the registry for the first time via a death certificate. The treatment records of the patient should be traced whenever possible. Only when no trace of the case can be found in hospital, clinic or laboratory records should it be included with the basis of diagnosis as 'death certificate only'. It should be noted that in the first few years of operation of a cancer registry there will be many such cases. This may dishearten registry staff. However, it is an inevitable consequence of using death certificates as a source of notification, since many deaths will relate to cases diagnosed years previously, who are not recorded in the registry, and records of whom cannot be traced. The percentage of such prevalent cases registered (erroneously in this case) via the death certificate will decrease quite rapidly after a year or two.

### *Data items to be collected*

The items of data which should be collected by a registry and suitable coding schemes have been described in Chapter 6. In this section, only considerations specific or important to the circumstances of developing countries are stressed.

The overriding consideration is that the list of data items should be as short as



possible. Before anything is added to the list of minimum items, summarized in Table 1 of Chapter 6, these questions should be asked:

- What is the purpose of collecting these data?
- Will the necessary information be available for most cases?
- Will it be possible to use the information in any meaningful analyses?

### **Recommended items**

(1) Index number (item 1).

(2) Personal identification number (item 2)—where this exists, and it is available for most cases registered.

(3) Names (item 3). It is essential to follow local practice in spelling, order etc.

(4) Sex (item 4).

(5) Date of birth (item 5). Where full date of birth is not known, the year of birth corresponding to the approximate age is recorded.

(6) Place of birth (item 7). Many developing countries have had large-scale internal migrations from rural to urban areas. Place of birth should be given in as much detail as possible, down to village.

(7) Address (item 6). This refers to the usual residence, and not to a temporary address. As for place of birth, as much detail as possible should be recorded to avoid ambiguity. In many countries, the dialect spoken and distinct aspects of life-style may be related to place of birth or to address, and in turn to differences in cancer risk.

As noted above, cancer registration is often restricted to large cities or the areas around them, since this is where the best medical facilities exist. It is in the same places that jobs are available, attracting selected groups of the national population, mainly young males with or without their wives and children. They may settle for weeks, months or years, perhaps even permanently. Whether they are considered to be residents can only be defined in terms of duration; the minimum time may be six or twelve months, for example. The population figures provided by a census are heavily dependent on the definition of residence, and cancer registries must use the same criteria for cancer patients. This may imply laborious investigations of the residential history of persons with cancer, to which physicians are unaccustomed. Nevertheless, the success of a cancer registry—or, rather, the scientific validity of its data—will depend upon the care with which an assistant clerk notes the residency of patients. Errors in the accurate recording of residence may result in dramatic overestimates of cancer incidence.

Demographers in census departments have considerable practical knowledge in training persons who are not highly educated to obtain demographic data, such as residence, age, ethnic group etc., and they are often willing to run periodic courses to train hospital admission clerks. Such a practice will ensure as much comparability as possible between the numerator data from cancer cases and the denominator data from the census.

(8) Ethnic group (item 11) or religion (item 12)—according to which is likely to be the more relevant for studies or variations in cancer incidence.

(9) Incidence date (item 16). The definition given in Chapter 6 should be adhered to. The date of first diagnosis, or date of first symptoms, should not be used.

(10) Topography (item 20). The site of the primary tumour should be recorded in words; if the site of the primary is not known, this should be stated. If the site of the primary is only suspected (on clinical or histological grounds), this should be noted.

Cancer registries using a computer should code topography of the primary tumour using the International Classification of Diseases for Oncology (ICD-O). This can readily be converted to the International Classification of Diseases (ICD-9) automatically, for the purpose of producing reports. However, for registries which will use manual filing systems, this is rather tedious, and the ICD-9 code can be entered in addition to that of the ICD-O.

(11) Morphology (item 21). This should be recorded in words in as much detail as possible, and coded using the ICD-O morphology codes. Note that behaviour codes /6 and /9 of the ICD-O should not be used by cancer registries (see Chapter 7).

(12) Most valid basis of diagnosis (item 17). The coding scheme in Chapter 6 is recommended. If there is no other data item which indicates that the case has been registered on the basis of data in a death certificate, with no further information available, the code 0: Death Certificate Only should be added.

(13) Source of information (item 35). The source of information should be noted, and a suitable coding scheme developed to embrace all the probable institutions or individuals who are likely to notify cases.

(14) Treatment (item 29). It is very rarely possible to collect many data on the type of treatment given, and in any case this information can rarely be used by population-based registries. If this item is retained, it is strongly suggested that the data collection is a very simple summary of therapy.

(15) Follow-up. As noted above, any type of systematic follow-up is very difficult for registries in developing countries. It is often not worth attempting to record anything under this item; the maximum worth attempting is the following:

– Date of last contact: this item is updated whenever any news of the patient (e.g., a subsequent hospital attendance, or death certificate) is received.

- Status at last contact: (1) alive
- (2) dead
- (8) emigrated
- (9) not known

– Cause of death. This should be coded as item 33:

- (1) dead of this cancer
- (2) dead of other cause
- (9) unknown

### *Data processing*

Most cancer registries in developing countries should aim to use a computer, since the price of microcomputers suitable for the purpose is no longer prohibitive. Suitable computer programs (software) are likewise available. These may be either commercially available data-base management software (such as DBASE), which is designed for recording any type of data set, or sets of programs specifically for cancer registries (see Appendix 4 and also Menck & Parkin, 1986).

For registries which must manage without a computer, a manual filing system will be used. The principles are described in Chapter 8. Essentially, this means that details of each registration are retained on paper forms or cards. These cards are most conveniently filed by registration number within each primary site, and it is often convenient to use different coloured cards for males and females. This greatly facilitates analysis of the registry, which normally will involve sorting by sex and site. In order to find any particular registration (so as to compare with an incoming case, or to update the information), a patient index must be maintained. This consists of a box of cards (see Chapter 8, Figure 2). Each card records, as a minimum: name, date of birth, sex, address, primary site of cancer and registration number. The cards are arranged in alphabetical order. This index is the main way of checking the registry file to find out if a newly notified case is already registered. A new card is added to the index for each new patient registered.

### *Procedures for a manual registry*

The procedures of cancer registration have been outlined in Chapter 8. Nevertheless, some aspects are more difficult in developing countries, especially the detection of multiple registrations of the same patient. This is due to the frequent lack of precise identifying information. Since date of birth is often not available, names, residence, ethnic group and site of cancer are used to detect duplicates. The search must be extended over several successive years, since cancer cases with long survival may appear several times. The high rates of cancers of the skin and of the uterine cervix reported in some developing countries are in part due to repeated inclusion of the same cases. Such artificial inflation of incidence rates may occur even with cancers for which a shorter survival has been reported, and investigators should be aware of the danger. Any new case resembling a case already recorded should be suspected of being a duplicate and all possible means of checking identity should be used. In order to restrict the size of the file which must be searched in order to compare with incoming cases, it is reasonable to restrict the active master file to cases registered within the last five years. The probability of recurrences or readmissions occurring after an interval of five years is quite small in developing countries, and the small resulting increase in duplicate registration is offset by the greatly reduced amount of file-searching. Somewhat more detail of the maintenance and storage of records and files in a manual tumour registry is given in *Cancer Registration and its Techniques* (MacLennan *et al.*, 1978).

The disadvantages of a manual registration system become more apparent when any attempt is made to analyse the data-base of cases registered. Any attempt to

tabulate and cross-tabulate the data involves sorting and piling of cards and documents, and is tedious, time-consuming and frustratingly prone to minor errors. Some of the problems are reduced by the use of edge-punched cards (described in MacLennan *et al.*, 1978). These can be sorted rather more rapidly, and permit more tabulations to be done, providing the file does not get too big. However, the investment in this rather tedious technology is not recommended, and every means possible of maintaining the register on a computer, even if shared with other users, should be sought.

### *Reporting of results*

Population-based cancer registries in developing countries should be able to report their results in the same way as those elsewhere (see Chapter 10).

Any report of results should attempt to describe the bias which may be present, including the relative over-representation of certain sites. Sources of underestimation are numerous and can be evaluated on the basis of the number of hospitals, medical services and personnel serving the population at risk. A detailed description must always accompany the data published. Overestimates may result either from insufficient checking for duplicates, from the inclusion of prevalent cases, from the inclusion of non-residents, or from an underestimation of the population at risk.

Unless it is quite certain that there has been no under-reporting of cases, conclusions can rarely be drawn from low incidence rates. Conversely, if sources of overestimation can reasonably be excluded, high rates may suggest that the type of cancer being considered is in reality even more frequent, since these rates are likely to be minimum rates.

For cancer registries that are not population-based, it is even more important to specify carefully the sources of cases recorded, and the differences which are likely between these and the cases occurring in the general population. The basic presentation of results will be a table showing the distribution of cases registered by site, sex and age (see Figure 1).

The distribution of cases by age for particular sites almost always takes a pyramidal form, and displaying these data graphically is rarely very informative. If the age structure of the population from which the cases come is known, even approximately (say, for example, as the population estimate for the entire country, or province), the ratio of cases:population can be calculated for each age group (Marsden, 1958). Plotting cases:population ratio against age is a substitute for graphs of age-specific incidence rates (see Figure 2)—it assumes that the biases operating in bringing certain cases to the registry are not related to age. Outside of the oldest age groups, this may sometimes be a reasonable assumption; for example, the percentage of stomach cancer cases biopsied, and so included in a histopathology register, may be relatively independent of age.

For comparisons of frequencies of different tumours in different sub-populations, or over different time periods, when the population at risk is unknown, comparison of relative frequency or proportions of the cancers must be used (see Chapter 11).

\*-- Male --\*

1980 - 1986 VANUATU

Number of Cases by age group

Site (ICD-9)	Unk	0-14	15-	25-	35-	45-	55-	65+	TOTAL	%
ALL SITES	-	10	3	14	16	23	37	15	118	100.0
143-5 Mouth	-	-	-	-	-	-	3	-	3	2.5
147 Nasopharynx	-	-	-	-	-	-	1	-	1	0.8
151 Stomach	-	-	-	-	-	-	1	-	1	0.8
153 Colon	-	-	-	-	-	-	1	3	4	3.4
154 Rectum	-	-	-	-	-	-	1	-	1	0.8
155 Liver	-	1	-	2	4	5	3	2	17	14.4
156 Gallbladder	-	1	-	-	1	-	-	-	2	1.7
157 Pancreas	-	-	-	-	-	1	1	-	2	1.7
162 Bronchus, lung	-	-	-	-	3	-	3	1	7	5.9
163 Pleura	-	-	1	-	1	-	-	-	2	1.7
170 Bone	-	2	2	1	-	-	-	-	5	4.2
171 Connective tissue	-	1	-	-	-	1	2	-	4	3.4
172 Melanoma, skin	-	-	-	1	1	-	1	2	5	4.2
173 Other Skin	-	2	-	2	4	7	9	2	26	22.0
175 Male breast	-	-	-	-	-	-	1	-	1	0.8
185 Prostate	-	-	-	-	-	-	2	1	3	2.5
186 Testis	-	-	-	2	-	1	-	1	4	3.4
188 Bladder	-	-	-	-	-	1	2	-	3	2.5
189 Kidney	-	-	-	-	-	1	-	-	1	0.8
190 Eye	-	-	-	-	-	1	-	-	1	0.8
193 Thyroid	-	-	-	1	-	1	2	1	5	4.2
200 Lymphosarcoma	-	1	-	1	-	1	-	-	3	2.5
201 Hodgkin's Disease	-	-	-	1	-	1	1	-	3	2.5
202 Other reticuloses	-	-	-	2	1	-	-	1	4	3.4
204 Lymphoid leukaemia	-	2	-	-	-	-	-	-	2	1.7
205 Myeloid leukaemia	-	-	-	1	-	-	-	-	1	0.8
PSU	-	-	-	-	1	2	3	1	7	5.9

Figure 1. Simple tabulation of cases registered, by sex, site and age  
 Data from histopathology registry in Vanuatu 1980-1986 (unpublished data courtesy of Dr N. Paksoy)

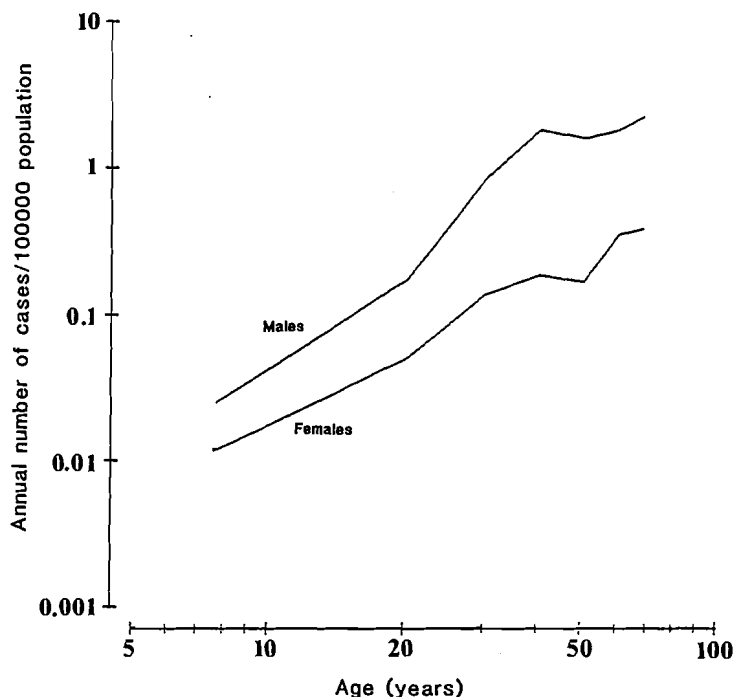


Figure 2. Ratio of cases:population, for Kaposi's sarcoma in Rwanda  
 From Ngendahayo *et al.*, 1989

### *Conclusion*

Cancer registration is an arduous task in developing countries, owing to shortages of medical facilities and personnel. The problems of identification of individuals, comprehensive case finding and definition of the reference population are most difficult to solve, and the risk of bias is always present.

It is wise to start simply. For some time, results may be reported in the form of relative frequencies by sex and ethnic group where relevant, rather than incidence rates. However, the ultimate objective should be to register cases from a defined population so that incidence rates can be calculated, even though these, initially, may be underestimates of the true rates. At this stage, cancer registration becomes much more rewarding, and this end justifies every effort to undertake the job, in spite of the difficulties.