Chapter 5. Data sources and reporting

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Initial evaluation

When setting up or reviewing the methods by which data can be collected—and these are manifold—it is of vital importance that any evaluation should establish:

(*a*) the true cost of each method of collection;
(*b*) the quality of data which it will provide;
(*c*) the uses which can be made of the data:
  (i) as soon as registration is complete,
  (ii) in the long term (20 or more years ahead);
(*d*) the constraints which will be placed on future research if:
  (i) items are not collected at all,
  (ii) items are collected in an abbreviated form;
(*e*) The problems which supplying information will cause in each and every contributing agency.

Further, these factors must be the subject of re-evaluation at regular intervals, since new methods or requirements will arise and others become obsolete.

Data sources

The main sources of information will usually be hospitals or cancer centres but, depending on the local circumstances, a population-based registry will also involve private clinics, general practitioners, laboratories, coroners, hospices, health insurance systems, screening programmes and central registers. Use of all these sources will ensure not only that few cases escape the net but also that the quality of the data is enhanced because every item relating to the patient is brought together in a single file. The use of multiple sources of information means, however, that multiple notifications of the same cancer case are likely to be received. Efficient procedures for linking data on the same individual are therefore very important (see Chapter 8).

The task of a population-based registry will obviously be much easier when there are collaborating hospital registries (see Chapter 13) which contribute information. However, even where these exist, the population-based registry must still utilize other

sources, firstly, to prevent cases being missed (such as patients never attending hospitals) and secondly, to assist in identifying duplicate registrations (for example, when a patient attends more than one hospital).

The possible sources available to the registry are discussed below. The use of all of these sources represents an ideal which, in practice, may not be achievable; nevertheless the goal should remain the incorporation of as many sources as possible. The actual methods used by each source to transmit information are discussed in the section on methods of data collection below.

Medical records department

The many ways in which such a department can contribute to cancer registration are discussed in Chapter 13. Here, only those aspects which will influence the completeness and accuracy of registration are considered. It is important that, whatever methods are used, each hospital is the responsibility of one person within the registry. This person should be responsible for monitoring returns from his or her hospitals and should note variations in either quantity or quality. As a result, omissions owing to changes in staff (clerical or clinical) or perhaps to the fact that new systems have been introduced can be detected at the earliest possible moment. It is only human to pay little attention to a hospital whose returns have always been excellent and to focus instead on the problem hospitals, only to find that a vitally important member of staff has left the former, with the result that efficiency has deteriorated and registration is no longer complete.

At every stage, it is necessary to consider ways in which cases may be lost. For example, a frequent method of identifying cancer records is for the records department to screen hospital notes on discharge of the patient, select those with a diagnosis (provisional or confirmed) of cancer and put these aside. It will be obvious that the efficacy of this method depends on all the hospital notes being sent back to medical records and on efficiency of recognition by their staff. Notes which are retained by the clinician, ward or unit may never reach the records department. This gives rise to many problems because, even if the numbers are small, there may be a high degree of selection, e.g., for a specific malignancy, special interests of individual clinicians, or coincidental disease or death.

Thus it is important to take account of such problems as the following.

(1) Patients on long-term treatment protocols, or frequent follow-up, where the notes may not be released. This particularly applies to haematological malignancies, but it is also noticeable that patients admitted to clinical trials are less likely to be registered, often because of extended programmes of chemotherapy.

(2) Patients suffering from tumours with slow progression. A differential diagnosis may not be made for years, or if made, it may be decided to observe the patient rather than undertake treatment. One example is melanoma of the eye.

(3) Patients with special sets of notes, only one of which contains the detailed information, e.g., diabetics.

(4) Specialized clinics which retain notes for a specific operation, e.g., laryngectomy clinic.

(5) Transplant patients. Again the notes may be retained by the unit and, should the patient subsequently develop a malignancy, this may never be recorded because the hospital notes do not follow the usual pathway.

(6) Patients admitted only for terminal care. Following the death of the patient, particularly if this occurs after a very short admission, there may be little interest in the notes and these may be filed without checking for a diagnosis of malignancy.

(7) With increasing pressure on space, the hospital notes of patients known to have died may be stored in inaccessible archives. Even worse, they may be stored out of order so that, to all intents and purposes, they are lost.

Outpatient clinics

In theory, patients attending as outpatients should be covered by one of the sources listed; in practice this is frequently not so.

A patient attending only as an outpatient will rarely have a biopsy (so this source of identification is lost); the notes may be inadequate and by definition, there is no hospital discharge abstract. Further, routine hospital returns do not always encompass outpatients.

If a patient is not admitted or investigated because the disease is terminal, then the case is likely to be picked up from the death certificate if these are available to the registry (see the section on death certificates below). However, a patient with a prostate cancer treated with stilbestrol may not die of cancer, even though it is present. Further an increasing number of patients (for example, those with gynaecological or skin cancers) are treated as outpatients by laser beam or radiotherapy, and in such cases there may not be a histological report.

The problem is complicated because the above, although numerically important in cancer terms, will form a very small proportion of the average outpatient case load. Hence their identification is very difficult—but they must be included to avoid bias and incompleteness of registration.

Private clinics and hospitals

In many countries a number of patients may be diagnosed and treated at privately owned nursing homes or clinics rather than hospitals. It is likely that these will need different arrangements for notification. Pathology reports are often particularly useful in identifying cases which might otherwise be missed.

However, since the clinicians involved are likely to be also on the staff of the local hospitals, they will be aware of the importance of complete registration.

Pathology laboratories

Wherever possible, registries should obtain copies of histology reports (for malignant or possibly malignant diagnoses) from each pathology laboratory in their area and these should be sent direct to the registry.

At the outset the method of identifying the reports required should be discussed with the head of the laboratory and, preferably, also with the staff who will select the

reports. If a histological code is allocated by the laboratory, this is one of the easiest ways of distinguishing registrable diseases. In addition—or where there is not a coding system—a list of terms should be agreed, for example, all cases where either cancer or malignancy is mentioned, together with any pre-malignant diagnoses which it is intended to register. It is preferable to accept doubtful cases, such as possibly malignant and sort these out centrally rather than risk losing borderline malignancies or those clinically malignant but with equivocal histology.

Difficulties which should be borne in mind are, firstly, if selection is by specific codes, any mis-coding may result in the cases being missed. This can be overcome by using the list of agreed terms described above as additional selection criteria, i.e., reports are sent if either the code is within the specified range or malignancy is mentioned. Secondly, if benign tumours of the central nervous system are registered (as is common practice for most cancer registries), there are a number of lesions where pathologists differ as to whether they should be considered as tumours or cysts. Agreement on which are to be notified and registered—and lists of the diagnoses to be notified—will avoid the registry wasting time in chasing notes which eventually turn out not to be registrable.

If a hospital registry exists, arrangements should be made for copies of pathology reports to be sent to both the hospital and the population-based registry. This apparent duplication is vital for two reasons—first, in maintaining uniformity over the years, and second, in ensuring that raw data are available in the population-based registry. On the first point, it is all too easy for staff changes in the hospital registry to affect efficiency of registration (a backlog of unregistered pathology reports will soon indicate this) and on the second, the availability of raw data considerably extends the range and accuracy of surveys that can be undertaken. This point is discussed further in the section on evaluation of sources and methods below.

It is essential that all types of pathology reports, including autopsy, bone marrow and cytology reports, are screened. Private clinics and nursing homes may have their own laboratories or use the services of private laboratories. It should also be remembered that in a large hospital there may be separate specialist departments (e.g., oral pathology, neuropathology).

Conversely, specialist departments may attract patients from outside the population normally covered. If so, great care must be taken to exclude these from analysis, although it may be helpful to register them separately in order to assess the workload or results of a particular specialty.

Perhaps surprisingly, the patient's name may be misspelt or be incomplete; if so, the report may not be correctly matched with other documentation relating to the same patient and thus duplicate registration occurs. Where computer matching techniques are available (see Chapter 8) then concurrence of date of operation or other factors may serve to identify the duplication.

Autopsy services

Autopsy reports provide a useful source of information. Particular attention should be paid to the influence on incidence rates of tumours only discovered at autopsy. A

special code should be allocated to such cases so that their effect on incidence can be evaluated (see Chapter 6, item 19). The number of tumours discovered at autopsy reflects, to some extent, the intensity of investigations carried out, as well as autopsy rates.

In some countries, the report from an autopsy on a death reported to the coroner may only be available from the coroner. If so, the registry should contact all coroners in the region to ensure that this source of information is not lost.

Haematology laboratories

These are an important source of haematopoietic malignancies such as leukaemias and lymphomas. The reports will usually come from a different laboratory than those for solid tumours and it is therefore important to ensure that separate arrangements are made for copies of haematology reports to be sent to the registry. The list of required terms may need to be expanded and it is likely that there will be more borderline diagnoses. Hence, discussion, and precise definitions of the diseases to be included are essential. Cytology reports should be included.

If the laboratory has a clinical pathologist who also prescribes treatment, then obviously his or her cooperation should be sought in obtaining details of treatment or other items needed by the registry. Again, notes for these conditions may be retained for long periods in the laboratory office and hence not picked up in the medical records department.

Other laboratories

A variety of biochemical and immunological tests which are of value in the diagnosis of cancer may be carried out by other laboratory services. They include, for example, measurement of serum and acid phosphatase (prostate cancer), serum alpha-fetoprotein (hepatocellular carcinoma), pattern of plasma proteins (multiple myeloma). Other tumour-specific antigens already in use have less diagnostic specificity for a particular cancer, but in the future they may be a useful source of information for the cancer registry.

As with all laboratory services, identification data are not always either accurate or adequate. Misspelling or insufficient identification (e.g., lack of data) may result in duplicate registration centrally.

Death certificates

A very important source of identifying cases is death certificates with mention of malignancy as one of the causes. Most countries have a system of death registration but, for reasons of confidentiality, the diagnosis may be entered on a detachable slip, which, if separated from the portion with name and other identifying information, makes this source useless for cancer registration.

A model death certificate was initially devised by the World Health Organization (WHO) in 1948; many countries have adopted this model, adapting it to their own

needs but conserving the principle of differentiating between the immediate cause of death, the underlying cause of death, and other pathological conditions present at the time of death but which did not directly cause it.

The cause of death is coded according to the International Classification of Diseases (ICD), using rules agreed upon internationally since 1948. The form of publication of results is likewise subject to precise rules, and the tabulations refer to the underlying cause of death.

From the point of view of using these items as a source of information about cancer, the principal goal of the system, which is to tabulate the cause of death, may present difficulties, since for cancer patients who die from other conditions or as a result of an accident, cancer may or may not be mentioned on the certificate.

Scrutinizing original (or copies of original) death certificates is much better than relying on the diagnostic lists of the vital statistics bureau. The latter are often coded only according to the underlying cause of death and may not include those deaths for which cancer was not the underlying cause. These details are important in obtaining the information sought by the cancer registry.

The diagnosis of the cause of death is often given in vague terms, and with regard to malignancies, the localization is very often mentioned but is not always correct, especially with geriatric patients. However, as the death certificate is usually made out by administrative authorities themselves, items of identity, such as dates of birth and of death and residence, are generally accurate. These elements are of particular importance if survival analysis is made one of the objectives of the registry.

Information on death is always of major interest for population-based cancer registries. Very often it is found that deaths from cancer relate to persons who have not previously been registered, and a follow-back must be started.

(1) For each death certificate relating to a death in hospital or to an autopsy, the pertinent clinical abstract will be requested from the hospital or pathologist.

(2) For patients not dying in hospital, the request should be made to the physician certifying death. This is discussed further in the next section. Some physicians respond much better to a telephone call than to a registry form. Since they may have been called in only at the terminal stage, their information that the patient has never been hospitalized may prove later to have been incorrect. For a population-based registry, it is recommended that all cases be registered, even if no other information is forthcoming. However, it is important that cases with no other information than the death certificate should be identified as registration from death certificate only.

Cases which are registered on the basis of the diagnosis cancer appearing on the death certificate, but for which the diagnosis is later proved to be wrong (for example by follow-back of clinical records, or at autopsy) are best excluded. If retained, they should be specially flagged, and not included in the analysis of incident cases.

The proportion of cases registered from death certificates only is often taken as an indicator of the quality of the registration process. It is recommended that cancer registries use the above definition of death certificate only (DCO) cases, i.e. cases for whom follow-back was unsuccessful and where the only evidence of a tumour is

provided by the death certificate. This common definition will improve comparability between registries. The cancer registry is well advised, however, also to monitor the number of cases that first come to the attention of the registry from death certificates; a high or increasing number may indicate insufficiencies in the reporting system (see Chapter 9).

Cases known from death certificates only may prove to be worth separate analysis. Since they may concern special groups of people, such as the elderly or certain ethnic or religious groups, avoidance of the use of medical services may be suspected. The validity of observed incidence rates (which, in fact, are always diagnostic rates) for such groups might then be questioned in the light of the proportion of cancer deaths not reported from any other source.

A follow-back of cases that first come to the attention of the registry from death certificates is of great importance in order to exclude prevalent cases when a registry first starts its operations. The accidental inclusion of some prevalent cases is, however, to some extent inevitable. If there are many such cases, it may be necessary to avoid publishing data from the first one or two years of the registry.

General practitioners

General practitioners are often the first to see cancer patients and to suspect the malignant nature of the illness. In most developed countries, as soon as there is a suspicion of cancer, they will send the patient to a hospital or cancer centre. The information available to the general practitioner is sometimes limited, except for that concerning the first symptoms of the illness and, possibly, antecedent data concerning the patient and his family.

When first seen, the patient may already have a very advanced stage of cancer, when all therapy would be futile, and the physician may decide against examinations, sometimes painful, which may be of minor diagnostic value. This applies especially to older people in developed countries and to people of all ages in developing countries. For such patients, general practitioners are the only source of information and would normally be the certifying physician on the death certificate, which in these cases is the principal source of information for the population-based registry.

As discussed in the previous section, on receiving a death certificate for which no registration exists, the registry should write to the physician asking for minimal but adequate information about the patient. The time of writing will depend on local conditions. In some countries, it is important to request information quickly before the notes held by the general practitioner are returned to a central office. However, a delay of say two months may mean the requisite information is received from the hospital without the need to approach the practitioner.

An alternative is to provide each practitioner with a small booklet of forms, together with reply-paid envelopes, for use when a patient is not referred to hospital. The forms will request sufficient information to register the case together with the reason for the patient not attending (too old, refused etc.). In the future, as more practitioners acquire microcomputers, it may be possible to generate a list of such patients routinely.

Health insurance (workers' compensation funds, etc.)

In many countries, systems of health insurance have developed either as complete national services, as obligatory insurance for an important fraction of the population, or as voluntary insurance.

In such systems, emphasis is placed on administrative documentation in relation to the refunding of benefits to the insured. Information of a medical character may be sparse and not very accurate; on the other hand, information concerning the identity items, the correct spelling of the name, date of birth, residence and successive occupations may be exact. In this respect, even if the medical information leaves much to be desired, insurance organizations are, in some countries, an important source for verifying data on the patient. Under certain circumstances, the health insurance organizations serve as intermediaries between the various sources of information and the cancer registry, since they assume the task of assembling all documentation relating to the insured. In this case, these organizations are a very valuable source of information, on condition that the obstacle of confidentiality can be overcome.

These schemes often have one major drawback from the point of view of registration, namely, that the identifying data pertain to the insured, while the illness may be in a dependent, e.g., a spouse.

Screening programmes

Such programmes have been set up in the course of the last 30 years to detect cancer as early as possible. The principal programmes are aimed at cancers of the uterine cervix and breast, but they have also been organized to detect and examine cancers in other organs, such as the bladder in workers in the aniline dye industry. Information, including details of cases of any cancers detected, from such programmes is held by those organizing them. It is generally easy to obtain information from these programmes, but the differentiation of invasive cancers from *in situ* carcinomas and other precancerous lesions usually requires further investigation elsewhere. The effect of including data from screening programmes needs careful evaluation, for example, in the assessment of survival rates. Furthermore, screening of asymptomatic persons may lead to the detection of tumours which may never present with clinical symptoms; the inclusion of screen-detected cases in the cancer registry may therefore lead to spurious increases in incidence rates.

Detection schemes for other diseases may become an important source of information; thus, the search for pulmonary tuberculosis by X-ray examination results in detection of some cancers of the lung and mediastinum.

Although screening programmes can be valuable as a source of cases, their effect on the comparability of incidence rates should be borne in mind. If screen-detected cases can be identified, the variable "method of detection" (Item 19, Chapter 6) may be used to compute incidence rates with and without such cases.

Central population register

Many countries have a central register of the entire population. In countries which have a national identification number or central alphabetical index holding details of

every person, this register is of prime importance. It may be advantageous to register identifying and demographic information from such an administrative central register, since its information is more correct than that in hospital records. The central register can be used to trace patients moving from one registry area to another and it can also be used for flagging possible risk groups; this aspect is discussed in Chapter 3.

Hospices

These homes for the terminally ill play an increasingly large part in the care of the patient. In general, most patients will have been seen at a hospital but, nevertheless, reports from hospices may identify cases who have previously been missed.

The majority of such hospices have relatively little clerical help, so requests for information should be kept to a minimum. However, if a death certificate is received and the case has not been registered, the hospice is usually willing to complete a simple form. It is particularly important to include the home address and the date and place of first diagnosis or treatment. These items will help to ensure that, if no other information can be obtained, then firstly, the case is included only if resident within the region and secondly, a reasonably accurate date is available (i.e., ensuring that incidence and not prevalence is measured).

Long-stay hospitals and homes for the elderly

Arrangements should be made for notification of patients from this type of hospital.

Methods of data collection

The earlier sections in this chapter described the sources of information available to the registry. There follows a note on the general aspects of routine medical documentation and then a discussion on some of the ways in which each source can transmit information to the registry. Traditionally, reporting methods have been classified as active or passive.

Active reporting (collection at source) involves registry personnel actually visiting the sources of data and abstracting the required information onto special forms, or obtaining copies of the necessary documents.

Passive (or self-) reporting relies upon other health care workers to complete notification forms and forward them to the registry, or to send copies of discharge abstracts etc. from which the necessary data can be obtained.

In practice, a mixture of these two systems may be used, with, for example, active hospital visits being supplemented by passive receipt of copies of pathology reporting forms and death certificates mentioning cancer.

Routine medical documentation in hospitals is extremely useful as a source of basic information; nevertheless, it does not generally meet the demands of a cancer registry. This is understandable, since cancer patients constitute only a minor fraction of all admissions. There may be little knowledge of, and little attention paid to, the particulars of special interest to the cancer registry. Notably, hospital systems are often based on patient episodes, whereas the registry is concerned with tumour

episodes—that is, with correlating all the information about the course of the disease and especially with ensuring that patients are not registered twice because of repeat admissions.

It is vital that the registry becomes familiar with the administrative practices and procedures, from admission to discharge, and with the existing filing systems. The admission clerk is responsible for recording identifying items and for their correctness and completeness. The person responsible for patient files may be the nurse or secretary in the ward, the nurse or secretary in the corresponding outpatient department, or a trained medical record librarian in a record room connected with all departments. The filing system must be understood, e.g., whether files of patients relating to successive hospitalizations are combined, and how the system can be used to check the completeness of reporting on all cancer cases seen in the hospital. In the case of an emergency admission, only minimal data may be on hand: it is not always realized that cancer patients may be admitted as emergencies, with obstructed bowel, perforated malignant gastric ulcer etc.

Based on this detailed knowledge the registry can decide on the items of information to be collected (see Chapter 6), and it can devise a system of collecting the information applicable to local needs but nevertheless providing high quality information for a tumour registry.

The medical records department is often the principal source of information. The principal source documents which can be used by the registry are:

specially designed registration forms;
copies of radiotherapy notes or summaries;
copies of discharge letters or case summaries;
hospital patient information systems.

These are not necessarily exclusive; for instance, it may be advantageous to use copies of radiotherapy notes for patients seen in the radiotherapy department but have a notification form for all other patients, since the latter will be seen in clinics dealing with many other diseases besides cancer.

In future, these source documents will increasingly be records on computer media rather than pieces of paper.

Specially designed registration (notification/reporting) forms

These are forms, designed by the registry, which provide a summary of the identification and clinical details required by the registry. They may be completed by hospital staff (consultants, registrars, secretaries, ward clerks, medical record staff, etc.) or by peripatetic staff from the registry. The great advantage of this type of notification is that because the information required is specified on the form it provides a standard set of data. Also, a relatively quick examination of the document will highlight missing items and enable early action to be taken.

Reliance upon receiving a notification form completed by hospital staff has the disadvantage that in the hospital it is often viewed as yet another form, and the accuracy with which it is completed can vary enormously. It must be acknowledged that, in general, medically trained staff are not the best people to complete such forms,

despite the value of their medical knowledge. Firstly, they may have insufficient time or inclination to complete the forms with sufficient care and, secondly, staff change posts so frequently that the vital element of consistency is lost. The latter point also applies to non-medical staff, so when changes of staff do occur, every effort should be made to train newly appointed staff either centrally at the registry or by visiting the hospital.

The advantages of peripatetic clerks employed by the registry to visit one or more hospitals and complete such forms are that the registry has direct control of the staff and can readily monitor the quality of returns. These clerks can also perform a very useful function in acting as liaison officers, including undertaking any training needed at hospital level, elucidating problems such as misspelt names and, most importantly, in making staff in the hospital (both clinical and clerical) aware of the registry as a source of information. Thus feedback of information is encouraged and, whether this takes the form of lists or more sophisticated analyses, it is by far the most effective way of improving the data.

Unfortunately peripatetic clerks may appear to be relatively expensive, although there are, as yet, no precise data on their cost-effectiveness in terms of quality of information. There is also a possible disadvantage in using external staff, since this lessens the involvement and commitment of the hospital staff.

Copies of radiotherapy notes or summaries

If these are available, this is an extremely efficient method of submitting data to the registry. Since the unit is dealing virtually entirely with cancer, the information is likely to correspond closely with that required by the registry. Problems which are likely to arise are that information on previous investigations and surgical treatment may be inadequate, but such information may not be collected by population-based registries. Further, many patients initially treated by surgery will be referred for treatment of recurrence or metastases. It is important that these should be identified to avoid inflating incidence rates by including prevalent cases.

Copies of discharge letters or case summaries

With continuing or increasing financial pressures, the cost of completing a special form—however desirable—may be prohibitive. In such cases, it is well worth investigating the quality of the discharge letter or summary which is often sent on completion of a course of treatment. If these are adequate, and many are excellent, then a carbon copy or photocopy can provide much of the information required.

The items omitted are usually the administrative ones. These can be obtained by devising an abbreviated registration form including only those details which are normally omitted from the discharge summary, e.g. further identification details, occupation etc. This form can be attached to the discharge summary before forwarding to the registry.

The advantages of this method are:
- it eliminates errors of transcription;
- the cost is small in comparison to the labour costs of completing a special form.

The disadvantages are:
- the quality and quantity of the data are unlikely to be consistent since the contents of discharge summaries will depend on the individual clinician;
- non-clinical items may not be given in sufficient detail;
- it will usually involve a number of secretarial and clerical staff who are often hard-pressed and who are dealing with a wide range of diseases
- in such circumstances, selection of malignant cases may be somewhat haphazard and some may be missed;
- the actual mechanics of obtaining a copy may be difficult, for instance, if the photocopier is some distance away, or, if carbon copies are involved, an audio-typist, on starting to type, may not know that the diagnosis is one of malignancy.

Hospital patient information systems

There are many ways by which hospitals measure their activity or workload and the registry should never neglect these as a possible source of data, not least because the aims of such systems are not only to include every episode but to do this as expeditiously as possible.

Where the hospital monitors the workload by coding information either on discharge or at the end of each episode, this can be an invaluable way of identifying malignant cases quickly. On selection, the information can then be transferred to the registry by means of a duplicate copy of the completed form, a printout for each patient or electronic transfer of the data to the computer used by the registry.

As discussed above, routine medical documentation of this type—however sophisticated—is rarely adequate for cancer registration. However, the system can be utilized in one of two ways.

(1) Routine documentation can be used to provide an initial registration giving accurate identification and administrative details (name, address, sex, age, hospital, hospital number, consultants), a provisional diagnosis and possibly an indication of the types of treatment.

This processed and coded information should then be supplemented by additional raw data. The extent of these will depend on the level of service which the registry is required to supply and thus, indirectly, on the research activity in the area. Items needed may include description of primary, stage, operative details and any adjuvant therapy. This clinical information can be transmitted to the registry by any of the methods described in this section and, together with copies of histology reports etc., will ensure centralized coding (with all the advantages that this implies). Of almost equal importance, it will also ensure that the basic information is available in the registry both for future research and for validation procedures.

(2) When this level of service and research is not required or is not feasible, the routine documentation can be supplemented by a much lower level of information. With this method, the coding is largely decentralized, being undertaken by the clerks responsible for all hospital routine data abstraction. Additional clinical information may be added by them either to a form or as a computer print-out but this information

is abstracted and therefore abbreviated. Hence any extended validation checks are virtually impossible. Further, since the emphasis is on speed, amendments of diagnosis will rarely be incorporated and this can be a considerable source of error, since the results of all the investigations etc. may not be available at time of discharge.

However, where interest or funds do not permit collection of detailed data, this provides a quick and relatively inexpensive method of registration. It is certainly more accurate than if the case is only identified at time of death. Its disadvantages lie in the decentralized coding and the lack of essential detail and of raw material for future research. This latter aspect will be even more important if the original hospital records are destroyed.

In both of the above, the biggest stumbling block is repeat admissions. It is essential that some method of linking repeat admissions or visits for the same patient be available. Further, it is vital that this operates whatever the time lapse and—where procedures have been computerized—takes account of admissions before the computer was introduced. Otherwise patients seen for metastases, possibly years after their initial treatment, will be registered as new cases. In consequence, they would improperly increase the incidence rate, whereas they should only be included in prevalence rates.

Instructions for reporting

Whatever method is used, it is advisable that each centre is aware of the rules and instructions for reporting cancer cases. These can be printed on the notification form, or may be incorporated in a special manual. The details will obviously vary with the registry's data requirements. The following requirements are based on the manual of the Danish Registry.

(1) A list of reportable diseases. This may be in the form of:
   (*a*) the International Classification of Diseases (ICD) categories required e.g., 140–208;
   (*b*) a list of the actual terms if the reporting centre does not use ICD codes.

(2) A list of episodes which should be notified.
   (*a*) all cases of newly diagnosed tumours;
   (*b*) all cases of multiple primary tumours, one notification for each tumour;
   (*c*) any revision of tumour diagnosis within the range of reportable tumours;
   (*d*) if a previous reported tumour by revision is not now a reportable disease;
   (*e*) any progression of precancerous lesions or carcinoma *in situ* to invasive tumours;
   (*f*) change of treatment within the first four months after primary diagnosis.

(3) Who is responsible for notification:
   (*a*) notification is mandatory for chiefs of hospital departments, when, for the first time, the department diagnoses, controls or treats clinically or microscopically diagnosed reportable tumours, irrespective of whether the tumour might have been reported from other departments;
   (*b*) general practitioners or specialists who begin treatment or have control of reportable tumours without referral to hospitals;

(*c*) medical doctors in charge of institutions, homes for the elderly etc. who diagnose a reportable tumour without referral to hospital;
(*d*) chiefs at departments of pathology, when a reportable tumour is diagnosed at autopsy or when a reportable disease previously suspected or proven cannot be found at autopsy.

(4) Guidelines on completion of the notification form.
(5) Name of contact in registry for problems.
(6) Name of contact in registry for results (i.e., lists or analyses).

Evaluation of sources and methods

It should never be forgotten that the ultimate aim in collecting data is for them to be used. For this reason each data source must be evaluated not only in relation to its use in effecting accurate and complete registration but also in relation to its usefulness in subsequent analyses and research. This is particularly important with increased computerization because, apart from identification particulars, data input to computers almost always entails simplifying it either by coding the information, or by condensing the script.

It is generally appreciated that these actions will entail the risk of errors and this aspect is discussed in Chapter 9. What is less obvious, and often forgotten, is the extent to which these actions may compromise future research if the raw data are not also available in the registry.

For example, the initial use of a histology report in a registry is to code histological type (e.g., to the International Classification of Diseases for Oncology, ICD-O), but the report issued by the pathologist will also often contain information about depth of penetration, nodal involvement etc. At the time of initial analysis, the ICD-O coding may be all that is required. However, subsequent research may, for instance, involve assessment of the prognostic value of depth of penetration. Where copies of reports are stored in the registry, such a project is readily undertaken, if necessary covering a long time-period. But if coding is not carried out centrally, and depends on a form or magnetic tape sent with the data already coded, all such future developments are impossible.

Further, because the raw data are not available, or are restricted if information is not coded centrally and submitted on magnetic tape, it will not be possible to carry out the validation checks which are feasible (with modern computers) when a single site is under review. Hence, if information is received in the registry already processed (e.g., on a magnetic tape, or cassette), these options of checking or extending the coding are lost.

Cancer registries are essentially collecting data for tomorrow's research and cancer control as well as today's. Hence it is vital that, when deciding on the methods to be used, the consequences of each choice should be the subject of the most careful consideration. Mistakes and omissions can rarely be corrected subsequently.