CANCER REGISTRATION
PLANNING AND POLICY

P. M. PAYNE, B.Sc.
Director, South Metropolitan Cancer Registry, Sutton, Surrey

The approach to this subject will first be to define cancer registration and to consider some difficulties that arise directly from this definition. Thereafter attention will be given to the problems associated with planning a cancer registry and with the formulation of a policy. Finally, an attempt will be made to look at the future of cancer registration.

A Definition of Cancer Registration

Cancer registration may be defined as the process of collating information about all cancer patients, or a statistically planned sample of them, in a prescribed population. Ideally this process should take place during the lifetimes of the patients.

Problems Arising from the Definition

Mis-diagnosis

It will almost certainly be impossible to obtain information about all cancer patients, since there will be many in whom the disease is diagnosed otherwise. Obviously, if these patients die without post-mortem examination, these errors are unlikely to come to light. Again, many patients may be registered as having cancer who, in fact, have some other disease. Errors of this kind may be rectified because of the course taken by the disease or as a result of further investigations or by post-mortem examination.

Definition of the Population

Most cancer registries set out to register all cancer patients in a prescribed population. As an alternative, however, cancer registration could be pursued on a sample survey basis, the fundamental principle being that each cancer patient has a known probability (in general less than unity) of being registered. The survey can be designed so that this known probability differs among the various groups of patients. But the probabilities are nonetheless known and in the case of complete registration the known probability is unity. Whether the census or sample survey approach is used, however, it is essential that the population be precisely defined.

If the population is indefinable or is badly defined, it is clearly impossible to say that a particular patient will be registered or, in general, that the probability of his being registered is equal to some known quantity. In consequence no general conclusions can be drawn. It is for this reason that cancer registration is most likely to be concerned with geographical populations or occupational groups where definition is not too difficult (though difficulties there are). An instance of an ill-defined population would be the population from which are drawn the patients coming under the care of a particular surgeon.

The same sort of criticism applies in decreasing measure to hospitals and to groups of hospitals. However, as the size of the unit under consideration increases, so does the concept of a 'catchment area', and hence of a well-defined geographical population, begin to emerge.

It is also important that dynamic information about the properties of the population should be available. By this is meant that there should be available up-to-date information about its size, its age and sex composition, its distribution according to occupation, racial groups, civil states and so on, not only for the population as a whole, but for its geographical or other subdivisions. Unfortunately, much of this information can be obtained only from census returns and censuses can of necessity be carried out only infrequently.

Mortality Prior to Registration

The final condition in the ideal definition is that registration should take place while the patient is still alive. It should, in fact, take place as soon as diagnosis is reasonably certain, but not so soon that large numbers of tiresome changes have to be made. The ideal definition cannot, however, be met because many patients die soon after first admission to hospital and previously unsuspected cancers are often found at post-mortem examination. The general principle whereby patients are registered while still alive must, however, be adhered to. Too much reliance on the use of death certificates during the period when the processes of formal registration are functioning only incompletely will cause the material to be biased towards the more lethal conditions.
Problems of Planning and Policy Formulation
Benefits in Relation to Cost and Effort

Probably the first question to be answered before embarking on a cancer registration scheme is 'Is it worth doing at all, quite apart from considerations of cost and practical difficulties?' If it is decided that it is worth while, an assessment must be made of the requirements, the likely difficulties and the cost. When this has been done the question must be asked again in the light of these forecasts.

It seems self-evident that when society is confronted with a very resistant problem the organization, not only of material resources and effort, but also of all relevant information, is desirable. Cancer is such a problem and cancer registration is simply the process of organizing the information about this problem. There are at least four major fields in which cancer registration should be able to make valuable contributions. These are epidemiological, clinical, therapeutic and administrative. In each field the contributions may appear in the form of routine periodic reports, the provision on request of information not covered in routine reports and in statistical research.

The epidemiological contribution is concerned with a study of variations in the impact of various forms of the disease from one population sub-group to another and with how this impact is changing with the course of time. The epidemiological applications of cancer registration may prove useful in suggesting hypotheses regarding the aetiology of some forms of the disease. It is, however, unlikely that the information collected in the course of registration will be conclusive in itself. A direct specialized study of the occupational or other population sub-group would have to be pursued as in the study of cancers of the urinary bladder in dyestuff workers (Case and Pearson, 1954; Case, Hosker, McDonald, and Pearson, 1954).

The clinical contribution will be concerned with such things as the symptomatology of the disease, its length of history and its extent and mode of spread.

It is necessary to be cautious about the inferences that can be drawn about the comparative values of different treatments on the basis of information derived from cancer registration. Patients who are treated by new methods will, in the early stages at least, be selected by reason of such attributes as their age, their fitness, their mental attitude and the nature and extent of their disease. Unless the, value of a new treatment is overwhelmingly obvious, inferences as to its value can only justifiably be drawn from the results of a properly planned and executed clinical trial. The organization carrying on cancer registration may well prove to be a suitable centre from which to direct such trials. Moreover, if the clinical trial should lead to the general adoption of a new treatment, then a measure of its overall benefit should be obtainable from cancer registration information over a period of a few years.

The administrative contribution derives to some extent from each of the three preceding fields and will be concerned with the nature, quantity and siting of cancer services.

Choice of a Population

The question of the choice of a population from which to register cancer does not generally arise. It is usually more or less determined by the extent of the authority of the organization seeking to institute the registration scheme. Thus a Regional Hospital Board would be concerned with the people living in its area. The boundaries of the region covered should, if possible, have real significance in a physical, ethnological or other special sense. Unfortunately, the Regional Hospital Board area boundaries in this country rarely have such significance and may often not coincide with the boundaries of local authority areas and areas defined for other purposes.

If a local authority area lies partly inside and partly outside a registry's area, and if there is a large general or teaching hospital in the excluded part, it is probable that people living in the included part will seek treatment at that hospital. The registration rate in the fractional area will thus be reduced unless some form of understanding exists with the hospital in the excluded part or with the registry which serves it.

One of the main criteria for the inclusion of a cancer patient in a registry's files is that the patient's permanent residence should be in the registry's area. Because the numbers of patients registered in various areas will be related to official estimates of populations for the purpose of calculating incidence rates, it follows that 'permanent residence' should have the same meaning as for official population statistics.

While some registries are interested only in patients resident in their areas, many include patients coming from outside their areas for investigation or treatment. Clearly, if a function of the registry is to provide statistical services for hospitals, these hospitals will expect the statistics to include those of its patients who live outside the registry's area.

Census or Sample?

 Apparently all cancer registries at the present time strive for complete registration. In most cases the registrations are only a sample because the process is still incomplete, but this is not a
designed sample in which each cancer patient has a known probability of inclusion.

Some form of sample approach may well come to be used, since it is often pointed out by writers on sampling techniques that so much more attention can be given to detail and to accuracy. Hence results may be more precise and less biased than those obtained by means of a complete census.

The sample technique might take one of the following forms:

(i) Only a sample of hospitals participates, but this sample changes from year to year.
(ii) Only certain diseases are registered in any one year, but these change each year.
(iii) All types of cancer are registered from all hospitals, but only a prescribed fraction of the patients with each type of cancer.

**General Practitioner Registration**

Registration of cancer is usually sought only from hospitals, but it is conceivable that a brief form of provisional cancer registration might be provided by general practitioners. Most of the cases so registered would later be substantiated by more detailed information from hospitals, possibly involving some change of diagnosis.

**Diagnoses to be Included**

The problem as to which diagnoses to include might have been regarded as a difficulty arising from the definition of cancer registration, since the term 'cancer' itself lacks precision.

Apart from the indisputably malignant tumours, the following are usually included: mixed salivary gland tumours, giant follicular lymphomas, mycosis fungoides and polycythaemia. Intracranial neoplasms are also usually registered whether or not they are histologically malignant. Tumours of doubtful malignancy should certainly be registered provisionally, since their inclusion can then be reviewed at any time. Some registries require or invite the registration of certain non-malignant neoplasms (e.g. papillomas of the bladder) because of the possibility that malignancy may supervene.

**Histological Confirmation**

Some registries concern themselves only with histologically confirmed malignancies, but most are too interested in total morbidity to impose such a limitation. In fact, it often happens that a patient is registered on clinical grounds alone in spite of a negative or equivocal pathologist's report.

In histologically confirmed cases the confirmation, and indeed the recorded description, of the tumour are generally those of the pathologist at the registering hospital. There are some registries, however, at which sections of tumours are received and reviewed by a registry pathologist. This eliminates much of the variation due to differences in individual interpretation, but is open to the criticism that it may cause offence.

**Multiple Tumours**

Registration is concerned with tumours rather than with patients, so that one patient with two primary tumours in different organs will be the subject of two registrations. If there is doubt as to whether two tumours are distinct primaries, it is probably better to regard them as such.

The case of multifocal tumours in one organ is more difficult. Generally one can do no more than register all such tumours as one and regard the recurrence of any one of them in the same way as the recurrence of all of them. Tumours of the skin merit special mention because, more than any other type of tumour, they are likely to be multiple. Cases in which patients incur 20 or 30 separate tumours are not uncommon, so that it would certainly seem impracticable to register and follow up each tumour separately.

**Estimate of Numbers to be Registered**

This estimate is necessary in order to get an idea of how large the staff of the registry should ultimately be and what provision for document storage and data handling will be necessary. A figure approaching 3 per thousand of the population is now being taken as a guide to incidence in this country. This may, however, be an overestimate for rural areas and for areas where there is a high proportion of young people. On the other hand, it may underestimate the incidence in highly industrialized areas, areas in which a strong aetiological factor exists and in areas where there is a high proportion of old people, e.g. in many seaside towns to which people retire.

To the figure calculated for patients living in the registry's area must be added an estimate of the numbers who attend hospitals inside the area, but who live outside.

**Arrangements for Registration at Hospitals**

The questions arising under this heading are as follows:

(a) What degree of obligation can or should be brought to bear on hospitals to register cancer? Should some financial reward be given for each registration?

(b) Who should do the clerical work involved by registration?

The degree of obligation may range from the statutory, as in countries and territories where cancer is a notifiable disease, to the completely optional. In the former case the great advantage is that complete registration will be achieved quickly. On the other hand, especially if some financial
reward is made for each registration, over-registration may result because of the difficulty of defining cancer. The optional approach has much appeal, though it may entail considerable exhortation and canvassing. Its success may well depend on the ability of the registry to provide an efficient statistical service for the hospitals from which the basic information comes. Its advantages are particularly appropriate to a group of diseases the aetiology of which is so diffuse and incompletely known. The optional approach leaves regional registries free to investigate problems of their choice in their own way and to vary their questionnaires from time to time as they see fit. This could hardly be possible if cancer were a nationally notifiable disease. It is, however, desirable that registries should co-operate strategically in the solution of specific problems.

Many registries owe much of their success to the fact that they have made financial reward for each registration, e.g. the Danish Cancer Registry. However, if the responsibility for registration in an area is to be shared among a relatively large number of individuals the fee must be chosen so that the average total remuneration is not trivial.

Information about cancer patients can be obtained from hospitals in a variety of ways. The ideal method might appear to be for doctors to complete the questionnaires at the time that they actually carry out their examinations and investigations. But this is not feasible when cancer is only one of many diseases being seen. Doctors might complete the questionnaires at some later stage when diagnoses are better established; for example, when the initial treatment has been completed. While it is often maintained that cancer questionnaires can only be completed properly by doctors, there should be a sincere desire to see that they are left as free as possible to carry out their main functions. An overworked or disinterested doctor is, in fact, much less likely to provide complete and accurate information than a clerk specializing in the work. But there are disadvantages in using clerks on the staff of the hospital for this purpose.

(1) Except at the larger hospitals, the task will not occupy the clerk’s full time and this means that other work of more direct concern to the hospital will be given precedence.

(2) The registry must be very tactful in asking for additional information or for information to be checked.

A solution may be to appoint field workers to the registry’s staff. This not only disposes of the above difficulties, but lends itself to uniformity of understanding through a short but intensive course of training at the registry. It is, of course, essential to provide for checks on time keeping, expenses incurred and work done, as well as on the proposed itineraries.

If there is any disadvantage in the use of field workers, it is that their working conditions cannot always be as good as one would wish. Hospitals may not be able to provide an adequate work place for an outsider when they often have little enough room for their own staffs.

Design and Content of Questionnaires

Cancer registries in general use one type of registration form for all cancers with provision for recording information up to the conclusion of the initial course of treatment. Some feel it necessary to have a somewhat modified form to cater for the reticuloses. A few have forms designed to elicit much additional detail about particular cancers. At the South Metropolitan Cancer Registry a single general form is in use (Fig. 1), but special projects for some sites are available to consultants or hospitals who are interested.

The information sought can be classified under the following headings:

(a) Basic information, e.g. age, sex, address.

(b) History and symptomatology, e.g. family history, possible causative factors, first symptom, date of first symptom, first consultation with general practitioner, etc.

(c) Clinical assessment, e.g. the clinical stage of the primary tumour, the involvement of lymph nodes and the presence of metastases (Harmer, 1958). Also the occurrence of any complicating conditions.

(d) Investigations.

(e) Diagnosis, including, if available, the histopathology of the tumour.

(f) Treatment.

(g) The source of the patient and where referred on completion of treatment. Also the arrangements for follow-up.

The amount of detail asked for at each stage must be carefully considered in relation to objectives. Thus, under the heading of investigations it may be sufficient merely to know that a particular investigation has been done. On the other hand, it may be necessary to know whether the result was or was not within normal limits. In some cases a record of the precise findings may be needed. Information as to the source and referral of the patient (g) may be important in obtaining more complete information.

The ‘organization and methods’ aspects of form design must not be overlooked (Milward, 1960).

While the form should be almost self-explanatory, it cannot be entirely so without making it appear rather wordy. For this reason an explanatory brochure should be available to hospitals and field workers.
Choice of Codes

This problem is closely allied to that of form design and the relationship between the two has been dealt with by Hogben and Cross (1960).

Coding, i.e. the translation of the information into numerical terms, is clearly necessary to meet the requirements of almost any data handling procedure. Much information that is directly numerical requires no coding, since it can be punched as it stands, e.g. ages, dates, durations and radiation doses. Sometimes, however, the numerical information will never be used in its original form, but only in terms of groups dictated by statistical considerations. In this case each group will require a code. ‘Duration of symptoms’ might be dealt with in this way, e.g. ‘less than one month’ might be coded ‘0’, ‘more than one month but less than three’ might be coded ‘1’ and so on.

Generally, where the number of possible answers to a question is small, these answers can be listed on the form with the code numbers against them. The person completing the form has then merely to ring the chosen alternative or place a tick against it and the code to be punched is immediately indicated. This is often called ‘self-coding’. The advantages of self-coding will be obvious, though it does tend to make questionnaires appear longer and more formidable.

Many questions do not lend themselves to self-coding because the number of possible answers is large. This may apply to such items as area of

![Image of the registration form]

**Fig. 1.**—General registration form in use at the South Metropolitan Cancer Registry. Above—Page 1. Opposite—Pages 2 and 3.
### HISTOLOGY

**OTHER COMPLICATING DISEASES**

- Small tumour limited to organ of origin—T1
- Larger tumour possibly with partial extension outside organ of origin—T2
- Ruptured or disseminated involvement of adjacent structures—T4

**REGIONAL LYMPH NODES**

- Not palpable
- Palpable mobile
- Palpable fixed

**BREAST ONLY**

- Hemisternal scapular or intra-mammary node involvement or Oedema of arm

**HIST.**

**OTHER TREATMENT**

### CLINICAL EXTENT OF DISEASE

**PRIMARY**

- Small tumour limited to organ of origin—T1
- Larger tumour possibly with partial extension outside organ of origin—T2
- Ruptured or disseminated involvement of adjacent structures—T4

**REGIONAL LYMPH NODES**

- Not palpable
- Palpable mobile
- Palpable fixed

**BREAST ONLY**

- Hemisternal scapular or intra-mammary node involvement or Oedema of arm

### SURGICAL/PATHOLOGICAL EXTENT OF DISEASE

**REGIONAL LYMPH NODES**

- Same examined
- Some examined
- Some not involved

### DISTANT METASTASES

**STAGE**

**SURGERY**

**DETAILS OF INITIAL TREATMENT**

**TREATMENT SUMMARY**

**OPERATIONS**

**APP. FLD. TCH**

### EXTERNAL IRRADIATION

**Radiotherapy**

**OTHER RADIATION**

**HORMONES & CHEMOTHERAPY**

**FINDING**

**HORMONES**

**CHEMOTHERAPY**

### FINAL ASSESSMENT OF TREATMENT

**PALLIATIVE**

**INCOMPLETE**

**UNTREATED**

**INTERSTAGE CYTOTHERAPY**

### COMPLETE BELOW ONLY IF PATIENT IS DEAD AT TIME OF REGISTRATION

**PLACE OF DEATH**

**DATE OF DEATH**

**IF NECROSIS DONE**

**ASSESSMENT OF PRIMARY SITE**

**METASTASES**

**SURVIVAL**

**OTHER ORGANS**

**DETAILED TREATMENTS PRIOR TO DEATH NOT REFERRED ABOVE**

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**Fig. 1. cont.**

**Page 2.**

**Page 3.**
residence, consultant, occupation and diagnosis, in which coding will be by reference to a manual. Certain other codes can be dealt with in a similar way or else can be simplified by making them specific to the diagnostic code. This might apply to the coding of the initial symptom and surgical operations.

The following are some codes commonly used for various purposes:

**Diagnosis**
- Committee on Hospital Morbidity Statistics, Medical Research Council (1944).
- Plunkett, R. J., and Hayden, Adeline C. (1952).
- World Health Organization (1957).

**Histology**
- American Cancer Society (1953).

**Occupation or Industry**
- ” ” (1958b).
- General Register Office (1960).

**Surgical Operations**
- Plunkett, R. J., and Hayden, Adeline C. (1952).
- General Register Office (1956).

**Data Handling Methods**

The consideration of methods of handling large volumes of data is by no means peculiar to cancer registration, so that a lengthy excursion here is not justified. Reference may be made to Casey and Perry (1958) and Payne (1959).

Unless the volume of cases for analysis is quite small, and unless the registration records are in the form of cards, they are unlikely to be directly amenable to hand sorting and counting.

The sorting problem can be solved by the use of edge-punched cards. Several registries have used this method successfully. It has, moreover, the advantage of avoiding the use of expensive equipment requiring skilled operators. However, it becomes cumbersome as the volume of records and the amount of information on each record increase, since the tedious business of counting the cards which have been sorted into the various groups remains. Although we are now on the threshold of the electronic data processing era, electro-mechanical punched card installations still predominate.

The punched cards used in these installations carry the information in the form of perforations in up to 12 positions arranged in a number of columns. The most useful contemporary card size is one of 80 columns, but equipment exists for which the cards have 21, 40 or 65 columns. At the South Metropolitan Cancer Registry 65-column cards are used, but information can also be punched in each column in 12 additional intermediate positions, so that the capacity of the card is equivalent to one of 130 columns (Fig. 2).

The types of machines generally in use have the following functions:

(i) Punching cards and verifying that punching has been correctly carried out.
(ii) Mainly reproducing existing cards wholly or in part.
(iii) Sorting and counting cards simultaneously.
(iv) Printing selected information from cards on to paper, usually in the form of continuous stationery.
(v) Printing information from punched cards on to punched cards themselves or on to adjacent punched cards.
(vi) Merging, selecting or comparing groups of cards.

A minimum installation would consist of machines of types (i) and (ii) and preferably of type (iii). A comprehensive installation would contain machines of all types.

Electromechanical punched card methods do not entirely eliminate the consideration of time. For example, it might be necessary merely as a preliminary operation to sort, say, 60,000 cards into an order determined by a three-digit code. This would therefore involve 180,000 card passages through a sorter. On a contemporary machine (though not the model affording the highest speed of operation) this would occupy at least five hours.

It is important to see punched card methods not only as an aid to analysis, but also as a means of eliminating much clerical drudgery. For example, a punched card is used at the South Metropolitan Cancer Registry to produce mechanically:

(i) The nominal index card.
(ii) An acknowledgment card.
(iii) A numerical index card.
(iv) The various annual follow-up requests.

**Follow-up Reports and the Use of Death Certificates**

Registries concerned primarily with cancer epidemiology may make no attempt to follow up patients. However, quite apart from the valuable information that comes out of it, any system which will encourage cancer patients to be seen regularly at hospitals or by their general practitioners will be beneficial in itself.

The two main policy questions to be answered regarding follow-up are:

(i) For how long and how frequently should patients be followed up?
(ii) What information should be sought at each report?

While much importance has come to be attached to survival rates and other statistics relating to special terms, such as 5 and 10 years, the World Health Organization has recommended that the results for a group should be given for yearly
intervals. This implies that follow-up reports should be obtained each year on or soon after the anniversary of the commencement of treatment. This does not, of course, preclude the patient's being seen more frequently as dictated by his condition or the nature of his disease, but it does lay down the minimum follow-up requirements for statistical purposes. For the more lethal cancers there may be some value in interpolating additional follow-ups at, say, 6 months and 18 months.

The total length of time for which a patient should be followed up is also a matter for consideration.

Ten-year results are the longest-term results commonly quoted, but provision is often made for follow-up reports at longer terms, say at 12, 15 and 20 years. It would, however, be generally agreed that such a long period of follow-up would be out of place for skin cancers, most of which recur within two years if they are going to recur at all. Two years or, at most, five years would seem to be a reasonable period for which to follow skin cancers, with the proviso that if a recurrence occurs in this time the patient can be followed for a longer period.

An economy which is sometimes practised is to call for the follow-up reports at intervals longer than the intervals between the reports themselves, e.g. at five years one might obtain an omnibus report for the first to the fifth anniversaries inclusive and at 10 years a report for the sixth to the tenth. One of the disadvantages is, of course, that one is denied the use of the follow-up information until it is actually obtained.

Regarding the nature of the follow-up information, the most useful single fact is the condition of the patient or possibly his inferred condition on the due date. This may range from the simple dichotomy—alive or dead—to some more elaborate classification involving the presence or absence of symptoms and recurrences and the capacity for work. In addition, if there is or has been a recurrence since the last report, it may be useful to know where it is—whether local or distant and, if distant, which organs were involved.

Further treatments for recurrences, too, should be noted though perhaps not with the same amount of detail as the initial treatment.

In the event of the patient having died, it is necessary to know the cause of death, whether cancer was present and, if so, where. It is also essential to know the survival time, whether a post-mortem examination was done and, if so, what the findings were.

It is often possible for cancer registries to be provided at, say, weekly intervals with copies of the death certificates of persons dying of cancer in their areas. In this country registries are helped in this way either by the Registrar General or by the Medical Officers of Health.

When the death certificates are received they can be checked against the nominal index of registered patients and so classified as either 'already registered' or 'not already registered'. In the former case the registry can notify the death to all those interested hospitals who may be unaware of it. In the latter case the registry can pursue enquiries with the general practitioner who signed the death certificate or with the hospital in which the patient died or at which he had been
seen and so secure registration of the tumour even if rather belatedly.

The death certificate procedure therefore enables a registry to perform a useful service to its hospitals and also to investigate and close loopholes in its own case-finding methods.

**Routine Reporting, Services on Request and Research**

It is all too easy for a registry to evolve without adequate facilities for the output of useful or interesting facts and so to become merely a highly efficient information gathering unit. This situation arises from the misconception that what remains to be done after punched card machines have produced the crude statistics is something quite trivial. But the calculation of percentages and more complex statistics, the search for what is significant or suspicious, comparisons with the experience of other places and times, the quest for explanations, the drawing of charts, the writing of texts—all these are far from trivial even when looked at individually.

The advent of electronic data-processing methods will no doubt bridge much of the gap between the output of raw data and the finished report, but with the data handling methods now generally in use there must be provision for computation, draughtsmanship, printing and editorial and secretarial requirements.

Routine reports are likely to be of three kinds: (a) regional, (b) hospital or hospital group and (c) anatomical. Aggregate regional reports should be simple and frequent, possibly annual. In addition to being statistical, they should serve to keep the personnel of the collaborating hospitals informed of the main procedural changes. Reports to individual hospitals or hospital groups should appear regularly, but less frequently than annually, possibly every three to five years. These reports should contain a section giving up-to-date information about the hospital or group, together with notes regarding any changes in the local policy and services relating to cancer investigation or therapy. Anatomical reports should deal with cancer of particular sites in greater detail and over a longer period than the annual regional report. Reports of this kind must be irregular by reason of the variations in the number of cases registered at different sites.

While inconsistencies between tables in the same report create a bad impression and should be eliminated, no reasonable critic must expect exact correspondence between two tables which are descriptively similar, but occur in reports prepared at different times. This is especially true of reports relating to cancer, since here we are concerned with a disease which is the subject of frequent revisions of opinion.

It is always well for registries to have a margin of resources enabling them to provide information on request to consultants and hospitals which has not appeared in routine reports. The ability to do this makes for good relations with hospitals and so in the long run improves the level of registration. While services relating to cancer are normally provided free, a registry may be embarrassed by frequent requests to undertake work not concerned with cancer. It may be wise to reserve the right to impose a charge for the provision of such services.

The policy of agreeing to provide cancer information on request can, however, act to the detriment of the registry in two ways. Firstly, it may provide this type of service so successfully as to overburden itself with this kind of work. Secondly, its reputation may be weakened through being unable to provide the required information. This latter situation must occur because a registry can plan at great cost to be able to provide answers to almost any questions only to be defeated at an encounter sooner or later.

These unforeseen questions should form the subject of the third kind of output from the registry, namely, research papers. These will in almost all cases be based on prospective enquiries rather than on existing records. The required information can be obtained as part of a special enquiry completely detached from the main cancer registration scheme or as part of the standard cancer questionnaire which is set aside for special purposes and may vary in content from time to time.

**Organization**

After all the foregoing problems have been considered it should be possible to determine the optimum organization for the registry and to estimate its immediate and long-term cost. If the cost appears prohibitive in relation to the likely benefits, the scheme may well be abandoned or re-planned on a more limited scale.

Of the various sections of a cancer registry, that concerned with follow-up will be the last to become static. This is because, even when complete registration is attained, follow-up work will continue to increase until the number of registered patients dying in each year is equal to the annual number of new registrations.

One part of this organization which has not been mentioned is the advisory committee, which is made up of representatives from the hospitals and administrative bodies which the registry serves. Such a committee is particularly necessary where the day-to-day management of the registry is not in the hands of medically qualified personnel.
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**PAYNE: Cancer Registration Planning and Policy**

**The Future Needs of Cancer Registration**

There are three main needs which must be met if cancer registration is to find a new level of usefulness in the future. They are (i) the need for advances in clinical and pathological semantics, that is, not only a growth in useful terminology, but in the acceptance of common meanings; (ii) a break-through in the methods of collecting and recording basic information in order to match the important advances already made in data processing; and (iii) collaboration between cancer registries.

**Standardization of Terminology**

Comparisons are often vitiated by the fact that people see and measure rather different things and, moreover, in classifying the things they see and measure they use either different terms or else the same terms but with different delineations of meaning. In pathology there seems to be this need for a common language. In descriptions of the clinical extent of cancers there seems to be a genuine effort not only to create a language, but also to see that clinicians agree in the use of the proposed terms. The difficulty in this case is going to be to get people to use the language. Some fundamental experimentation seems to be needed in order to find out to what extent and for what reasons clinicians and pathologists disagree in the classification of the phenomena they observe.

**Recording Information**

Reference has been made to the possible increase in the use of electronic data processing for cancer registration and similar problems. Certainly the time must be at hand when a typical medical record can be represented on perhaps 2 or 3 in. of magnetic tape and when many thousands of such records can be scanned and processed every minute. The great obstacle appears to be that the methods of obtaining the information and making it available to a computer have not kept pace with the development of the computers themselves. The business of obtaining the information remains a matter of asking questions, of carrying out investigations, of reading and of writing down or typing answers and results. All these are essentially personal activities and, although work study is being applied successfully to them, the extent of any improvements is of a much lower order of magnitude than the advances in data processing. There must be major advances in this field if full advantage is to be taken of computer techniques.

**Collaboration Between Registries**

One registry working in isolation is of much less use than many registries working with full knowledge of the methods, conventions and findings of others.

There is a need for collaboration of a more active and personal nature than the mere exchange of literature. By way of example, it is conceivable that one registry may observe something unusual in a part of its area in which the terrain, the population or its activities has certain properties. The registry may have no similar area which might serve to assist its inferences and in these circumstances the collaboration of another registry could well be useful.

This article has considered only the planning and policy aspects of cancer registration. There are, of course, a host of problems which cannot be dealt with here and which arise in the implementation of the policy; that is to say, in the field of management and operation.

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P. M. Payne

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