THE CURRENT AND FUTURE USE OF REGISTERS

IN HEALTH INFORMATION SYSTEMS

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INTRODUCTION

In many countries registers have been established for a number of diseases. Sometimes the possibility of establishing a register has been considered but rejected because of a lack of knowledge of how to develop such an activity. Some registers were set up without any clear objectives at all. For others the purpose was not sufficiently clearly formulated at the outset, so that the data collected were not the most suitable. Certainly some registers were established where the basic data on which they could be built were incomplete or inaccurate, where diagnostic methods were uncertain, and where there were not enough suitably trained personnel to maintain the register, nor the necessary staff to analyse and appraise the statistical material which registers can produce. Hence valuable time and effort were expended without compensatory results, so that some registers have already been closed down because they were expensive to run and did not do what was required of them. Consequently there has developed a certain feeling of disillusionment with the disease register as a tool.

There is, however, no valid reason for rejecting a useful implement just because it has sometimes been used for the wrong purpose or because the method of handling it is not fully understood. The purpose of this study is to examine the possible uses of disease registers in studying the epidemiology of diseases, the protection and surveillance of sick persons and the evaluation of various kinds of treatment, for the planning and evaluation of services, for education and for research purposes.

The conditions under which registers may best be established are next considered. These include certainty of diagnosis in the disease which it is proposed to register, availability of trained staff at various levels, possibilities for follow-up and facilities for data processing and interpretation. The study then describes the difficulties which arise in establishing and using registers. These fall under three main headings, relating to case-finding and the decision of who and what to register, to the follow-up of patients which is one of the primary purposes of setting up disease registers and to problems of organization. A practical example of the steps to be taken in setting up a disease register is shown and illustrated from WHO’s experience in helping a group of countries to establish registers for ischaemic heart disease.

Finally an analysis is provided of the replies made by a number of Member States to a questionnaire about their own experiences in developing and trying to use disease registers. WHO is grateful to those who have made suggestions for the action to be taken in order to assist Member States in the more efficient use of disease registers. Such help might include, for example, instructions for developing registers for individual diseases, training of registry staff, organizing workshops for health statisticians in the methodology of analysing registry data or working with groups of countries in the development of pilot registries.

It is hoped that this paper will go some way towards answering the questions and resolving the perplexities aroused in developing and exploiting disease registers. It must however, be clearly understood, that a register should only be set up when no more economical method can be found for answering the questions posed. It is unfortunate that some registries have produced data which could have been obtained equally well, and much more cheaply, from census returns or from routinely collected admission and discharge data for various kinds of health service. No universal rule can be formulated with regard to the establishment of a register, since each register will be developed to reply to a particular question or need. This will determine the data to be collected and the methods of analysis to be employed.

1 The information provided by the countries that replied to a WHO questionnaire on existing disease registers and their purposes is given in Appendix 1.
I. WHAT IS A REGISTER?

The simplest concept of a register is a list in which each item is individually identified. Thus school registers contain the list of names of children who are attending at a particular period, while land registries identify plots of ground. Most countries now have a registration system for births and deaths, and in each case sufficient information must be included in the register to enable each individual to be uniquely identified. When annual statistics of births are prepared, this identification of the individual is lost as statistics refer to groups of people.

However, more details may be included in the registration than are actually needed to identify an individual. Death registration includes the cause of death because of the importance in medicine of cause of death statistics. In its widest sense a register may perhaps be described as: a file of documents containing uniform information about individual persons, collected in a systematic and comprehensive way, in order to serve a predetermined purpose. Thus while it is only necessary to record that a uniquely identified person is dead in order for his heirs to receive their inheritance, the opportunity may be taken to record on the certificate the age at death, the cause of death and other data judged essential for the predetermined purpose of tabulating deaths by cause.

Disease registration is a rather more difficult concept, because a disease cannot be considered for registration purposes independently of the person who falls a victim to it. Registration must not be confused with notification. Infectious diseases must be notified to the appropriate medical authorities in order that certain public health procedures may be set in motion. Two or three smallpox notifications in a district will often be sufficient to produce mass vaccination campaigns. Although at the time the authorities are interested in the identity of the individual who has smallpox, this is a temporary interest concerned with tracing his possible contacts in case they should develop and help to spread the disease. Once the outbreak is over, the personal identification of the individual who had the disease ceases to be important. He becomes "a case" and in the study of the epidemic it is the temporal and spatial relationship between cases which are of primary interest; there is no need to maintain a permanent register of people who had the disease.

The eleventh report of the WHO Expert Committee on Health Statistics stated:

"The term 'registration' implies something more than 'notification'. A register requires that a permanent record be established, that the cases be followed-up, and that basic statistical tabulations be prepared both on frequency and survival. In addition, the patients on a register should frequently be the subjects of special studies."

It is clear from this statement that keeping a register will involve case-finding, follow-up and statistical utilization of the data obtained. This implies the unique identification of each person who presents a case of the disease, the establishment of a permanent record of all such people, including the recording of such data as are necessary for identification purposes, the collection of subsequent data for each individual in relation to the course of the disease or to the prevention of relapses.

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i.e., follow-up, and the preparation of basic statistical information about the patients when they are placed on the register and its review at stated intervals thereafter.

None of these processes is easy in itself and taken together they impose a heavy burden in terms of finance and personnel. A register should not be set up if there are other less expensive ways of solving a problem. For example, many infectious diseases are subject to compulsory notification, and if the notification system works well the study of variations in the routine annual statistics of notified cases will supply valuable information about the epidemiology of a disease and the effects of a control programme. If, however, the disease has after-effects which may appear at various times, or if maintenance of therapy is necessary to effect a cure (as in tuberculosis) or to prevent a relapse (as in rheumatic fever) it becomes necessary to establish a register, to permit follow-up studies or to see that treatment is being given.

The concept of registers remains the same even though the name itself is not used. For some people the word "register" has unpleasant connotations. This is so in psychiatric illness where patients may be compulsorily detained in hospital and where it is felt that registration implies a kind of stigma. Other terms such as "index", "control programme" or "follow-up study" may be used. Some descriptions of programmes of continuing treatment do not mention the registration of cases, although it is apparent that the programme will only succeed if there is a local or central register which is continually checked to ensure that patients are remaining in contact. The discussion in this paper, therefore, applies to any system which conforms to the definition of a register, whatever it is called. Registers can take various forms. For example, an index card may be established at the time the patient is admitted to the register; this will include items such as name or identity number, sex, age, civil state, address, etc., which are required for the unique identification of the patient. Date of admission to the register is also essential, since all patients should be followed up at the same time-intervals after registration. The dates and results of follow-up investigation should be recorded as well. The cards in such a register may be arranged in alphabetical order, or by subcategories of the disease studied. Alternatively the register may be maintained on computer tape, provided sufficient space is available for each individual for the results of follow-up investigations to be added. The data for a register may be obtained either by actually interviewing or examining the patient or by record linkage. Registers of individual diseases may in their turn be linked to build up complete morbidity registers of defined populations or services.

Most registers have been set up to deal with only one disease such as cancer, tuberculosis, or ischaemic heart disease. A practical point that arises when such registers are established is whether to record other conditions present at the time of registration and also intercurrent diseases which may affect the patient during the follow-up period. Most morbidity statistics are published by single diagnoses, so that the same person may appear several times in a set of annual tables. In the same way, he may be included in several registers; this might happen for example to a blind diabetic who developed lung cancer. Disease registers as at present constituted do not usually offer an opportunity to study the way in which combinations of diseases occur in man. At present, death registers are among the few places where these combinations are recorded but the data have not been fully exploited. However, where registers are to be used to evaluate services, it may be important to know of concurrent and intercurrent diseases since they may affect the outcome. For example, from a psychiatric register it is possible to find how many patients are discharged within successive periods after admission and how many remain continuously in hospital. The efficiency of a hospital will be judged by a swift discharge rate and low chronicity ratio. The proportion of long-stay patients with other handicaps is important, because while a schizophrenic patient may be discharged, the prospects for discharging a schizophrenic who is also blind or epileptic or mentally retarded are considerably reduced.
A survey of registers to be used in health information systems must take into account not only people who have a disease, but those who are likely to have it, with the aim if possible of primary prevention. For example, a person is at risk of developing diabetes if some of his near relatives are diabetic. Similarly, efforts are being made to identify at birth children who may develop deafness or cerebral palsy. However, in establishing such registers it is important that the high-risk conditions should be rigorously defined, or registers become so inflated that they defeat the purpose for which they were designed.

Registers of twins, especially if based upon birth records which identify multiple births, can be very useful in the study of the epidemiology of chronic diseases and they are gradually becoming more used for this purpose. They have the advantage that pairs of identical twins, who have the same genetic constitution, can be studied for response to different environments, while non-identical twins with their different genetic make-up can be studied for the effects of similar environments on different constitutions.

Disease registers must depend in large part for their success upon exact methods of diagnosis. It may, therefore, be necessary to develop ancillary registers which are intended to help promote reliable diagnosis and classification. Tumour registries are an excellent example. They serve as an international means of communication, for example in the evaluation of therapy and the estimation of survival rates. Sets of colour transparencies of pathological tissue are sent by WHO to all recognized medical schools giving in each case the diagnosis in the four official languages (English, French, Spanish and Russian). The terminology and nomenclature given are those agreed upon by experts in the field and have the best chance of being internationally accepted. Similar efforts are being made in cytology to standardize the names of individual cells, for example in the sputum.

The term "register" can be used in a wide variety of ways to denote a tool useful in the study of many diseases. It is important that any group of investigators wishing to develop one should first define what they mean by a disease register in their particular information system. The next requirement is a statement of how the registered population is to be limited, for example with reference to a group of services or to a place. This population will be subject to change. Over a period some individuals will be taken off the register, e.g., those who die, who are cured or no longer at risk, and those who were wrongly registered in the first place, while others will be added. At the same time there will be changes in the status of the registered individuals themselves, for example through relapse, or the development of secondary conditions. Statistical analysis of these changes will be required and should be planned at the inception of the scheme.

Secrecy is essential in the maintenance of a register. Not only must registry staff be well instructed in this essential matter, but also care must be taken that no unauthorized person gains access to the register. Statistics produced from it will refer to groups of patients and be tabulated in such a way that it is impossible to identify any individual. However, registers contain much information of importance for research, especially where a physician is studying the outcome of treatment. In this case it is customary to distinguish between absolute secrecy and medical secrecy. The latter prevents the release of information to an unauthorized person and for other reasons than for the good of the patient, but allows information to be divulged to other physicians when this is thought to be in the patient's interest. When a patient moves from one service to another, X-ray photographs may be passed on or the case-history record itself. Similarly, in reply to a request for follow-up data, it may be possible to say whether the patient has been admitted to hospital and if so, between what dates. If more information is required, it is necessary for the person responsible for the register to obtain permission from the hospital and from the individual concerned to divulge the patient's whereabouts. If permission is granted, the physician carrying out the follow-up study can then apply to the hospital, either for more information or for permission to interview the patient. As an unauthorized leakage of data may result in a refusal to supply any further details, it is impossible to be too careful about maintaining the secrecy of the registered individuals.
It is essential to show how a register fits into an overall plan for community control of a disease. The register must promote the aims of a programme, and must not be regarded as an end in itself. Everyone concerned must know what part he has to play and why. To ensure this is important for all registers where the staff are either doctors or medical auxiliary workers, and may be expected to understand the purpose for which the register is being set up. It becomes more imperative when registers are automated and specialists in fields outside medicine have to be brought into the programme.

II. WHAT PURPOSES DO REGISTERS SERVE?

Statements about what purposes registers can serve or are expected to serve may differ widely, even among a group of people maintaining registers for the same disease. At a Seminar held in 1965 on Automation of Rheumatic Fever Registries and attended by representatives from various American states, the following statements of purpose were made by different participants:¹

(a) Primary purpose: to provide local health departments with information on the prophylaxis status of their patients who are reported to have rheumatic heart disease or as having had rheumatic fever during the past 10 years.

Other purposes

(i) To provide the state with an estimate of types and quantities of drugs which must be ordered for the next federal year.

(ii) To instruct physicians in the proper diagnosis of rheumatic fever.

(b) Primary goals

(i) Assisting the physician in the follow-up of patients on prophylactic medication.

(ii) Providing low-cost or free medication for needy patients.

(iii) Obtaining information about the incidence and prevalence of rheumatic fever and rheumatic heart disease.

(iv) Distributing current literature and other information about rheumatic fever and rheumatic heart disease.

(c) Purpose

(i) To provide free sulfadiazine or penicillin to patients who have had rheumatic fever and who are unable to purchase prophylactic medication to prevent a recurrence.

(ii) To continue medical supervision by requiring yearly physician renewal of prescriptions and by asking the local public health nurse to check periodically adherence by patients to medication.

(d) The registry can be looked at in terms of the classic medical school triad of research, service and teaching.

(i) Research - statistical and epidemiological data which theoretically a good registry can generate.

(ii) Service - follow-up programme in the illusive goal of preventing rheumatic fever occurrence.

(iii) Teaching - community and physician education which the very existence of a rheumatic fever programme tends to produce in some degree.

(e) Purpose

To provide drugs for the prevention of recurrent attacks of rheumatic fever.

(f) Purpose

The registry is for secondary prevention; prevention of recurrent rheumatic fever and the associated increased risks of fatal heart disease. It will be purely or primarily for the aid of the physician in the care of his patient.

These statements of purpose have been quoted at some length because they show a number of interesting features about the participants' concepts of registry utilization. No doubt all would agree basically that patients who have had rheumatic fever once are likely to have recurrent attacks and to develop rheumatic heart disease unless they are maintained on prophylactic penicillin, and that it is the duty of the health services to see that they are so maintained. Yet some registries seem to be limited to patients who cannot afford to buy their drugs, regardless of the fact that those who can purchase medication may not do so, or may not take their drugs.

There is a division of opinion about whether the registry is to help the local health authority or the individual physician. A rather wide range of secondary aims also emerges, i.e. estimating incidence and prevalence; educating physicians in diagnosis; estimating the size of the drug order; public education about rheumatic fever and heart disease; statistical and epidemiological research.

While all these aims are excellent in themselves, they may tend to obscure the ultimate purpose of the register. For example, an epidemiologist may be so occupied in using the register to study the epidemiology, ecology and etiology of rheumatic fever that he may quite overlook the necessity for home visits to find out whether the patients are getting and taking their medication. It has to be emphasized that the ultimate success of a rheumatic fever register is the prevention of recurrences.

Disease registers are not a novelty, although at present the possible uses of registers are being considered for a much wider range of conditions than was at first envisaged. Cancer and tuberculosis were subject early to registration procedures. In Denmark a first attempt at cancer registration was made in 1905, when physicians were asked to report all patients under treatment. In 1942 the National Cancer Registry was established with the support of the National Health Service and the Danish Medical Association. In the United Kingdom registration was begun in 1930 by the Radium Commission which was established in 1929 to control the supply of radium to radiotherapy centres and to evaluate the use of radium in the treatment of cancer. With growing interest in cancer registration, a group of European workers met in Copenhagen in June 1955 under the auspices of the National Anti-Cancer League and with approval of the Danish Health Service; 10 countries were represented.

At this meeting it was stated that:

"the principal aims of cancer registration are to obtain information on (a) incidence and (b) subsequent course of registered cases".

It was noted, however, that the emphasis placed on these two aims varied widely between different countries and was reflected in their methods of collecting the data. Among the contributions to the discussion was one from Dr J. Clemmesen, Director of the Danish Cancer Registry, who stated that the aim of his registry at its opening was to collect material which could serve as a basis for:
(a) reliable morbidity statistics with a view to the accurate estimate of therapeutic results in cancer;

(b) an estimate of differences in incidence of cancerous diseases at various times and in various areas, occupations, etc.;

(c) statistics on individual persons for the use of physicians, as well as for the study of multiple cancers and coincidence with other diseases.

The Cancer Registration scheme in the United Kingdom was expected to give "valuable information" on "the following important subjects":

(a) the incidence in relation to site, sex, age and area of residence;

(b) delay in seeking medical advice and coming under treatment;

(c) extent of disease when first diagnosed;

(d) methods used in main treatment;

(e) proportion of cases treated radically;

(f) overall survival in relation to site, age and sex;

(g) survival rates:
   (i) by different methods of treatment and where no treatment is given;
   (ii) as affected by the extent of the disease when first diagnosed;
   (iii) of radically treated cases with histological confirmation of malignancy compared with those not so confirmed;

(h) interval between earliest symptoms and death;

(i) incidence of two or more primary malignant growths in the same patient.

This statement is important because it simultaneously indicates what it is hoped to find out and the kind of statistical analysis that will be undertaken.

In 1956 Dr Harold Dorn visited Egypt as consultant to the WHO Regional Office for the Eastern Mediterranean to investigate the possibilities for cancer registration and statistics there. His report quotes from the Manual for Cancer Programmes of the American College of Surgeons as follows:

"It must not be overlooked that the cancer programme is basically a two-phase activity, first the statistical aspect and second, the clinical aspect, both contributing to each other yet separate in their purpose and function."

He further stated that cancer registration in accordance with the above principles can serve the following purposes:

1. The determination of the incidence of cancer by age, sex, primary site, etc. This information is essential to measure the magnitude of the cancer problem and to understand more adequately the nature of cancer as a disease.

2. Measurement of changes in incidence and mortality over time.
3. The regular follow-up of treated cases in order to provide adequate medical care.

4. The evaluation of the results of different methods of treatment and of variations in the results of treatment in different treatment centres.

5. A basis for planning programmes for early detection and diagnosis and for evaluating the success of such programmes.

6. A basis for detailed epidemiological studies of the etiology of human cancer.

Dr Dorn concluded that if the above principles for cancer registration were accepted, it was immediately apparent that "cancer registration for all or even a substantial part of Egypt is impracticable at the present time".

The above examples have been quoted because they serve to show how, once the idea of a disease register is accepted, the purposes that it is expected to serve tend to proliferate, while at the same time, the basic means for obtaining a comprehensive register, let alone developing any statistics from it, may be altogether lacking in many countries.

Before examination of the conditions under which it may be profitable to establish a register of any disease, an analysis may first be made of the purposes which disease registers can be expected to serve.

1. Identification of individuals

In its simplest form the central registration of patients can be useful in identifying persons suffering from diseases, thus enabling a physician studying the condition to obtain access to patients in significant numbers when that would not be possible through his own practice or hospital. For example, through the Psychiatric In-patient Index, maintained by the British Ministry of Health, a psychiatrist engaged in research into Huntington's chorea was put in touch with the medical superintendents of the hospitals where such patients were already in residence or where new cases were admitted. Similarly, the British Medical Research Council's Genetics Unit was informed where it could find a case of Down's syndrome in a patient born of consanguineous parents.

Another example of the use of a simple register of individuals is that made by blood transfusion centres of their registers of donors to facilitate supply of blood of the less common groups in an emergency.

Registration can also eliminate double counting. For example, a child may be registered locally for two different congenital malformations, but in a central registry this fact will be detected and corrected. This is important in estimating the overall prevalence rate of congenital malformations or any handicapping conditions, several of which tend to occur in the same individual. The elimination of double-counting is also important in calculating the administrative incidence of mental disorders, where the organization of services is such that the same person may appear for the same total spell of sickness in both the inpatient and day-patient records, and possibly twice in those of outpatients, i.e., before and after the inpatient care. It is not, however, a primary function of a register to obtain an unduplicated count of all persons being cared for at a given time, as this can be done more quickly and cheaply by taking a census and eliminating those who appear more than once on the list.

2. Immediate protection of the individual

The purpose of such registration is to protect the individual from avoidable consequences of his disease. Thus persons who are registered as diabetic may receive an identifying card of a certain colour. Then if they are found unconscious it can be easily seen that the loss of consciousness may be due to administration of too much or too little insulin, and
appropriate measures can be taken. Similar identification of persons with haematomorphyria will warn that they should not be given barbiturates or sulfonamides, as they may develop an acute illness in consequence. The World Federation of Hemophilia encourages registration, those suffering from this condition being given an identification card useful in case of accident.

Some registers may be purely social. For example, blind persons may be registered because they are entitled to social support from the welfare services and often to various statutory and other financial benefits and concessions. Such registers are not useful for ascertaining the incidence or prevalence of blindness, because only people wishing to receive the benefits will register.¹

3. Surveillance

For a number of diseases it is necessary, once they have been diagnosed, to institute a prolonged period of treatment or prophylaxis. In this case a register has to be set up and a means found of ensuring that medication is received and taken. It has already been noted that all persons who have had rheumatic fever require prophylactic penicillin or sulfadiazine in order to prevent a recurrence and so decrease the likelihood of their developing rheumatic heart disease. In the case of children this medicatin should continue until they become adults.

One of the problems of long-term therapy is to maintain the patient's motivation for taking the drugs. Disease registers are useful in such cases because one of the items to be recorded will be the date on which the patient last collected his supply of medication; defaulters can thus be identified and home visits made, to confirm that there has been no relapse and to remotivate the patient.

Phenylketonuria is another condition requiring the surveillance of the patient for an extended period. Infants at birth can be screened and all those with very high concentrations of phenylalanine in the blood need to be fed with treated protein hydrolysates from which phenylalanine has been selectively removed. This treatment must continue for the first five years of life in conjunction with regular analyses to find the blood phenylalanine level and with observation of the patient who, in the absence of this treatment, may show mental retardation. (See Appendix 1 for a specimen form for routine blood-testing for phenylketonuria.)

Surveillance is also important when a "high-risk" group has been identified, as repeated examinations of subjects likely to develop a disease may lead to early detection and treatment. Thus Hoover & Fraumeni reported in 1973:²

"Among 6297 individuals reported to a kidney-transplant registry, the risk of developing lymphoma was about 35 times higher than normal and was derived almost entirely from a risk of reticulum-cell sarcoma, which was 350 times greater than expected. The excess lymphoma risk appeared within a year of transplantation and remained at the same high level for the five or more years of follow-up. Skin and lip cancers occurred up to four times more often than expected. Other cancers were 2.5 times more common in men only, due largely to soft-tissue sarcoma and hepatobiliary carcinoma. This excess risk of other cancers appeared later than that for the lymphomas and became more pronounced as the interval since transplantation increased."

4. Epidemiology

Since a disease register is an index of people who have, or had, the disease in question, it is perhaps natural that it should be expected to supply epidemiological information. In particular for the earlier registers of tuberculosis, rheumatic fever, and cancer this aspect of utilization was emphasized.

Thus the Danish Tuberculosis Index (as opposed to the Central Register) was envisaged primarily as a research office whose main task would be long-range, nationwide studies of the epidemiology of tuberculosis. The Register, it was thought, could control the notification system. It would be possible to report the incidence and prevalence of the disease, and also the number of cases confirmed by bacillary evidence.

Similarly it was expected that cancer registries would be able to provide information about tumours of various sites for a defined population. They would provide an accurate estimate of the differences in the incidence of cancerous diseases at various times, in different places and occupation groups. A rheumatic fever registry might be expected to generate statistical and epidemiological data about the incidence and prevalence of rheumatic fever and rheumatic heart disease. It was felt, especially in relation to cancer, that a population-based registry would provide information about cases which did not come to hospital, and thus come closer to giving a true epidemiological picture. Some of the protagonists of registration nevertheless realized that the true epidemiological picture is not likely to emerge from registers, which can only record cases that come to attention in one way or another, but which will leave a small proportion of "hidden" cases undetected.

5. Planning, operation and evaluation of services

The introduction of national health service programmes paid for by per capita insurance contributions levied on large sections of the population, or of private insurance schemes similarly funded by fixed personal premiums may have helped to stimulate an interest in estimating the services needed and evaluating their effects. In the first place it was felt that the reliable morbidity statistics which should be obtained from disease registers would measure the extent of the disease problem, especially if they were population- as opposed to hospital-based. Knowledge of even "administrative" incidence and prevalence, particularly when based on a trend over some years, would help to indicate the numbers for whom services had to be provided.

So far as cancer is concerned, it was felt that long-term follow-up studies would provide a valid measurement of success in treatment, by finding the diminution of the excess mortality risk associated with particular forms of cancer. If data from local cancer registries were fed into a central registry, the latter would be able to compare survival rates for example between institutions using mainly radiotherapy and those where surgery was preferred.

Similarly in the case of rheumatic fever registries, they would be the basis for estimates of the extent to which the existing programmes were preventing relapse and so weak areas or programmes would be detected and those responsible could be urged to improve their efforts.

For acute myocardial infarction it has been pointed out that evaluation of therapeutic and preventive measures will be impossible if data about occurrence, distribution and prognosis are lacking. A register will not only indicate the number of emergencies with which the services will have to cope but, by recording the time of day at which they occur, it may also show periods of highest demand so that arrangements can be made for the greatest mobilization of intensive care teams at these periods. Long-term follow-up of registered cases is the best way of evaluating programmes for the care of coronary patients and their rehabilitation. The success of the services can be judged by a small reduction of about 20-25% in the death-rate, but especially by the decrease in the time interval between the onset of infarction and the patient's return to work.
Psychiatric registers can also provide a useful means of evaluating treatment. The aim of modern services is to maintain the patient in the community as long as possible, treating him if necessary in out-patient clinics. Hospitalization should be a last resort and the patient should be restored to his place in society as quickly as possible. Routine admission and discharge data sheets, used for preparing annual statistics, can be built up into a register from which it is possible to calculate the total time for which a patient is hospitalized, irrespective of the number of times he is admitted. The same "risk-time" can be given to each patient, for example one or two years from the date of contact. The application of double decrement tables to cohorts of admissions can be used to plan the number of beds required for hospital treatment and, by showing the residue of patients continuously in hospital for specified periods, can demonstrate whether the services are reducing the number of potential long-stay patients.

6. Evaluation of treatment

The registration and follow-up of patients is a useful tool for the evaluation of new drugs, and also of the efficiency of treatment of various groups of patients by existing therapy.

Mention has already been made in connexion with the epidemiology of tuberculosis of the Danish Tuberculosis Register for which it is claimed that the variations in the numbers of new registrations afford a measure of the efficacy of different types of prophylactics. Tuberculosis registers can also be used to evaluate chemotherapy applied to potential cases of tuberculosis, by showing the number of verified cases which occur.

Amoebiasis is another condition in which registration and follow-up are necessary for the evaluation of new drugs. A number of forms of chemotherapy are in use against various types of amoebic infection and for two at least (niridazole and metronidazole) it is claimed that they are effective against all forms of the disease. In the evaluation of medication it is important that the diagnostic criteria should be clearly defined, that the dosage and method of administration of the drug should be recorded, together with any other medication likely to affect the outcome. Patients are expected to remain in hospital for a certain number of days after treatment has finished. Cases should be followed up, for example in the case of amoebic dysentery after one month and again at two and three months after discharge, so that relapses may be identified.

In the case of trachoma it is desired to test the effect of treatment campaigns in areas where only schoolchildren were treated compared with those in which therapy was given to the whole household. In this case registration is required to ensure the identification of subjects throughout the test, since a period of at least three months and preferably six should elapse between the end of treatment and the assessment of results.

Registers of patients who receive certain kinds of drugs are also necessary in determining the risks attached to therapy. For example, it is important to register and follow up women treated with hormonal contraceptives, in order to detect in the long term the possible occurrence and course of malignancy of tumours of the breast and genital tract in such women.

7. Research

There are a number of conditions in which registers can serve a useful purpose for research into the development and course of diseases for which the stages of control and hence ultimate eradication have not yet been reached. Some of these involve genetic studies and the identification of high-risk groups. In other examples it is hoped to find an association between several diseases occurring in the same individual, with a view to elucidating the etiology and organization of the particular malady. It is clear that registers of this kind would have to be maintained over long periods of time.
The development of maternal and child care services, which among other things may result in the preservation of infants who might formerly have died in the perinatal period, has led to a number of questions about the possible effects on children of adverse incidents during pregnancy or delivery. The future intelligence level of the child is of particular interest. Such studies depend for their success on the registration of a large number of cases, as only large cohorts will provide a sufficient number of affected children.

Thus the Perinatal Research Branch of the American National Institute of Neurological Diseases and Stroke, with 14 collaborating centres, registered about 56,000 women and their obstetric records. The children were examined periodically for an evaluation of mental and physical developments; speech, language and hearing were assessed and childhood illnesses and injuries surveyed. At eight months and again at three years psychological evaluations were made. Another collaborative study on this register made by the National Institute was concerned with cerebral palsy, mental retardation and other neurological and sensory disorders of infancy and childhood. It was found that maternal diabetes had an adverse effect on the neuropsychological attributes of the children. A study made in Newcastle, England, involving 4,000 children a year born at 28 weeks or more to local mothers, utilized the records of the Local Health Authority Visitors to record the usual important milestones for the children's first two years of life. When the group on this register entered school at the age of 5, they were given a series of tests to measure coordination, hand dominance and IQ. It was found that lowered IQ was associated with placenta praevia.

Similar studies, for example in Aberdeen, Scotland, sought to establish the relationship between obstetrical and perinatal factors and subsequent mental retardation in the children. The National Child Development Study being carried out by Dr James Douglas in Britain includes a first cohort of one week's births in 1946 who are being followed continuously. A second cohort began in 1958, and those registered received their first follow-up in 1964, so that information on most children would be obtained when they were seven years of age. The objects of this study are to continue to follow up the progress of these subjects so that for those who at birth might be considered "at risk", possible latent effects could be evaluated and the subsequent history of those identified as handicapped could be investigated. Registers of this type are major undertakings, especially in the efforts which have to be made not to lose cases. They may also generate, as side-products, a great deal of information about what happens to a group of people at various stages of their passage through life, but this has to be examined in relation to external factors, full or underemployment, war or peace, and ecological situations which are not likely to be repeated. Such registers are typical of those about which it would be asked whether the primary objects could not be, just as effectively but rather more cheaply, accomplished by other methods.

The difficulty of trying to find significant associations of factors in pregnancy and delivery with subsequent maldevelopment in the offspring needs to be appreciated, and "fashions" in medical research must be carefully evaluated before being adopted. Thus the Report of a WHO Scientific Group on Biological Components of Human Reproduction states:

"The 'at-risk registers' of the child population currently compiled by many health authorities in more developed countries often include all children whose mothers' pregnancies were characterized by ante-partum haemorrhage, pre-eclampsia of all degrees of severity, prolonged labour, operative or assisted delivery, abnormal presentation or premature delivery, as well as all children of low birth weight and those exhibiting signs of distress at birth. Such inflated registers defeat the purpose for which they were designed."2

2 Author's underlining.
Another field of utility for registers is that of genetic research. For example, it is desired to establish a registry of patients with chromosomal aberrations in order to find the incidence of such aberrations and the survival characteristics of patients who have them. From this it is hoped to find out in which chromosomes lie the specific genes responsible for the transmission of pathological conditions. In the case of some birth defects, however, the part played by genetic factors in their etiology is not completely understood and it is necessary to distinguish between genetic factors and environmental factors which adversely affect the intrauterine development of the fetus. To help solve this problem twin registers have been established. It is recognized that chronic diseases are very complex and influenced by many environmental factors.

"In addition, it may be assumed that environmental factors will affect individuals differently according to their genetic make-up. It is apparent therefore that in the study of chronic diseases epidemiologists must go beyond their previous important, but obviously insufficient, approaches. They should begin to orient their thinking towards the contribution that population genetics can make to epidemiology. In fact they must recognize that such epidemiological problems can be fully elucidated only if genetic factors are considered and studied concurrently with environmental factors.

Twins may offer particularly good opportunities for such studies. The two members of a pair of identical twins have the same genetic make-up and permit studies of response to different environments; on the other hand, the two members of a pair of non-identical twins are genetically different and can give some insight into the effect of similar environment on different constitutions."\[1\]

But whereas in the past twin studies were based on limited numbers of pairs of twins, nowadays for epidemiological purposes more than 2000 or even 10 000 pairs may be registered. The importance attached to twin registers in medical research is demonstrated by the replies to a questionnaire sent out by WHO in 1965 to investigators known to be engaged in twin studies involving fairly large numbers of pairs. This showed 39 twin series covering about 60 ongoing or planned research projects. The number of series has since been revised to 47.

Studies based on twin registers can have a significance for preventive medicine. For instance, in some diseases such as diabetes if one of a pair of identical twins develops the disease the chance that the other twin will do so is increased.

A second advantage of genetic studies is that they make it possible to offer genetic counselling for a number of conditions. Probably in all countries not less than 4% of live-born individuals suffer from a genetic or partly genetic condition; in some parts of the world this proportion is much higher. At least 1% of all infants have a major chromosome abnormality. Genetic advice is necessary, firstly because the severity of the conditions may have a very disturbing effect on the families, and secondly because such counselling may lead to early diagnosis which in its turn may ensure early treatment.

There are several other diseases for which registers could be useful. For example in toxoplasmosis the pathogenesis of the congenital disease needs to be investigated, with follow-up studies of the children. The determination of antibodies in the amniotic fluid of pregnant women suspected of toxoplastic disease should be undertaken and their babies should be registered and followed up to show whether the appearance of antibodies in amniotic fluid indicates infection of the fetus.

**Schistosomiasis** is a disease which afflicts a large part of the tropical world but whose importance as a public health priority has been questioned. Mortality and morbidity

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statistics have been of little value in this connexion. What is not clear is the way in which some pathological lesions are related to the infection, because they may be found in patients who are not infected as well as in those who are. Cross-sectional studies may determine the incidence of such lesions as ureteric deformity and hydronephrosis, but registration of the cases found and follow-up for an indefinite period are necessary to show the consequences. While the registered population may be reviewed at intervals, it is essential for any major illnesses in the patients to be notified early and particularly for deaths to be reported at once and autopsy material made available. From the study population it may be possible to find the rate of onset of various lesions and complications and, by using one group as a control, to find the effect of treatment on the outcome. From the long-term study of individual patients the suspected relationship between schistosomiasis and bladder cancer might be investigated.

It will be seen from the examples above that ultimately considerable rewards may be reaped from the institution of registers for the long-term study of a number of diseases the etiology, course and outcome of which are at present uncertain. It is also apparent that the setting up and utilization of such registers may be a complicated task. The question of who should set up research registers and where they should be established will be discussed later.

8. Education

Although registers are not primarily established for educational purposes, both the maintenance of a register and the information derived from it can serve this end.

The establishment of a register is useful in educating physicians in diagnosis, since it is essential that the cases being registered are the ones required and not "false positives". Usually the record sheets for setting up a register will contain questions about the basis of the diagnosis, and instructions about which cases to include. Registry cases, therefore, are likely to be better diagnosed than the general run of patients diagnosed for routine morbidity statistics. For example, it is well known that chest physicians who are asked to read the same X-ray films after a certain lapse of time, will often reverse their previous decision completely. For tuberculosis registers it is essential that the diagnosis should be bacteriologically confirmed, because the register will then consist of open infectious cases.

Tissue and bone tumour registers are a valuable aid to correct diagnosis, and help to improve the efficiency of cancer registration.

Registers also encourage those who work on them to be more accurate in carrying out their tasks. Every year an enormous quantity of medical statistics is compiled and published, and very little is known about the quality of the data on which these statistics are based. However, since many theories and even expensive research projects are established on the basis of statistical findings, it is important that their quality should be as high as possible. In handling large numbers of the same type of record it is easy to make a few mistakes here and there that are not noticeable in the bulk statistics presented in tabulations. When a patient is being followed up, however, the data recorded at registration will be checked by that obtained at subsequent examinations. It is soon realized that the work involved in correcting mistakes can be avoided by means of greater accuracy in the first place. The efforts needed to ensure complete registration make people aware that the health authorities are particularly interested in the disease in question. Once interest is aroused, case-finding becomes easier, and publicity can be given to the need for seeking advice and coming under treatment as soon as possible. To make registration campaigns as effective as possible, it is essential to have statistics from the follow-up of registered cases, showing how early treatment can reduce the death and permanent disability rates and recurrences. This kind of information is very important in the case of cancer, for example, where people are reluctant to approach the doctor, but it can only be obtained from the follow-up of registered cases. In developing countries the arrival of a health worker on a follow-up visit to a patient may cause a large part of a village population to turn out and see what is happening. Where
diseases such as tuberculosis require long-term surveillance of registered cases and defaulters must be detected and visited, there are excellent opportunities for public education.

9. Other uses of disease registers

Reference has already been made to the need for establishing an international register of human chromosome anomalies, which will assist genetic counselling by the detection of heterozygous carriers of detrimental genes. The recipients of such counselling should also be registered and followed up at regular intervals so as to see whether the advice given was reliable, how far it had been followed and in what ways.

Another use for disease registers is the development of methodology; what has been done for one disease is often applicable to others. Thus the need to estimate survival rates for cancer patients, a group who were early subject to registration, led to the development of a methodology which can be used in studying survival rates in a number of other diseases. At the same time, the need for record linkage, on which some of the more complicated registers depend, has led to the development of methods for file updating, data retrieval and tabulation. In building up a psychiatric register, for example, not only must hospital records be used, but those of outpatient clinics, day hospitals, night hostels and other places where patients make contact with the medical services, and also of social security agencies, schools, the police, hostels and many voluntary welfare societies. In setting up a psychiatric register for patients in a part of London with a population of about 17 500, some 60 case-finding sources were used. Such registers are difficult to establish, but once they are working they should be exploited for a whole variety of purposes, epidemiological, methodological, research and evaluative. Only in this way can their cost be justified. The maintenance of secrecy, as described in section 1 above, is essential for such registers.

It may have been gathered from subsection 7 above on the use of registers for research, that many chronic diseases will only yield the secrets of their etiology and prognosis when subjected to sophisticated methods of investigation. It may well be that one of the greatest values of the disease registers as they exist at present lies in the education they provide in the exact determination and recording of essential data about patients and their diseases.

In conclusion, it may be said that there is considerable awareness of what disease registers might do. Some have been established for many years, some are in their infancy and others are at the planning stage. However, it cannot be assumed that because a registry has given valuable results for one disease it will necessarily do so for others. International communication is so well developed, and students from developing countries are so often able to see on the spot what is being done in countries with vastly greater resources than their own, that they may be misled into thinking that they should set up disease registers, when in fact the diseases for which these have been established elsewhere are not among their most pressing health problems. In any case, existing registers need to be critically examined to see if their performance has matched their promise.

III. THE "WHAT?", "WHO?", "WHERE?" AND "WHEN?" OF DISEASE REGISTERS

As a preliminary to deciding what diseases should be registered, who should establish registers, where they should be set up and when it is desirable to run a register, the first point to be considered is whether it is going to be possible to obtain the information required. For example, it is no good planning to set up a psychiatric register based on linking records by patients' names, only to find that the local professional organization or the superintendents of several hospitals refuse to participate in something which they think violates the rights of the individual. This raises the question of whether registration should in some or all cases be made compulsory. Here registration must be carefully distinguished from notification. Many infectious diseases are notifiable, either because even a single case constitutes a threat to public health or because the notification statistics help to show whether prophylaxis programmes are working properly. It is more difficult to make chronic diseases subject to compulsory notification because it is not so
much their presence that is hazardous, but the strain they impose on health services generally and the economic loss they engender. Compulsory registration is equivalent to compulsory notification and no doubt would help to make case-finding more comprehensive. But the notification of chronic disease is not likely to lead to immediate action by the health services and is therefore harder to justify. It is no doubt for reasons of this kind that while most people would agree that some kind of cancer registries are desirable, so far as can be ascertained only one country has made cancer registration compulsory. Another difficulty is that compulsory registration involves legislation and unfortunately victims of disease are often more prone to feel they are being legislated against rather than legislated for.

Apart from more detailed practical considerations, it is also necessary to consider whether there are any cultural factors involved which could prevent successful registration. For example, if valid diagnosis can only be made from examination of the blood, it is of little use to try to set up a register in a country where a considerable proportion at least of the population refuses to have its blood sampled. The same applies to diseases where autopsy is essential but the relatives refuse to give permission.

Since maintaining a register essentially involves following up patients, whether there is any entitlement to recall or visit an ex-patient for follow-up purposes must also be considered at the onset. Re-examination may be justified if it offers a service to the patient; the post-operative cancer patient can appreciate the value of recall for the early detection of recurrence or of secondary growths. It is more difficult to ask psychiatric patients to come for follow-up; if the patient has a relapse he will be readmitted to care anyway; he may be in a situation where it would be disadvantageous if he were identified as an ex-mental patient, and it may do him no good to recall difficulties and painful symptoms which he may well be trying to forget. It is for reasons of this kind that psychiatric registers may be best maintained by record linkage.

To avoid future disappointment, therefore, the general possibility of instituting a register is the first thing to be considered. The next step is to decide on the characteristics that indicate the suitability of a disease as a subject of a successful register.

1. **Certainty of diagnosis**

Since a register relates to a specified disease, the first requirement is that the disease chosen can be diagnosed with certainty. It should be possible to describe the disease in unequivocal terms so that there will be uniformity of diagnosis among all physicians engaged in registering cases. Such uniformity will be easier to achieve in one hospital than several, in a hospital than among a group of general practitioners, and in one country than in many. It may even be necessary, at the outset, to conduct a substudy to see if uniformity in diagnosis can be achieved and then to recheck the uniformity of diagnosis periodically. In particular, any new members of a registry team need to be trained in the diagnostic methods used; in cases of long-term registries such as rheumatic fever and cancer this can be quite a large task.

Uniformity of diagnosis may be still more difficult to achieve when the register planned is to be population-based. Shortage of medical manpower for screening the population may lead to the use of paramedical personnel for case-finding; for example, if medical students screen for mental disease, not only may their judgements be more subjective than those of trained psychiatrists, but their results will differ because behaviour that does not vary very much from the normal range is more likely to impress less experienced personnel than their more experienced colleagues. Another difficulty is that whereas an affected individual is one who lies beyond the tail of the normal distribution, not only may the normal distribution not be known, but it may vary from one country to another.

It should be easier to diagnose a disease for which there are laboratory tests, provided the apparatus is there and in working condition and that those who are to use it know what to do. But as it has been sadly remarked about some tuberculosis registries - "the laboratory
is not working, or they don't know how to take the sputum, so saliva may be examined instead. Another problem with a disease such as tuberculosis where registration and follow-up are essential for control, is whether a public health agency can do the work of validating the diagnosis and possible recurrences of the disease with accuracy. But even where reliable diagnostic tests exist, there is still the problem of establishing whether the level of the test results is uniform for establishing the diagnosis in the case of a disease which is worldwide. This question arises, for example, in relation to the glucose tolerance test (GTT) in diabetes. Even under optimal conditions, it should be considered whether the establishment of a register for a particular disease is likely to place an intolerable strain on laboratory or radiological resources.

Whereas the incidence of many diseases is fairly continuous, although subject perhaps to seasonal or cyclical variation, other cases may occur quite sporadically. As a result, they may be missed because those who should make the diagnosis have not seen a case before.

Methods of diagnosis which depend little upon subjective factors may be preferred for some diseases. For example, in developing countries it may be better to diagnose cancer on pathological rather than clinical evidence. In some such country all cancer diagnosis is based on what can be seen under the microscope.

Another problem in relation to diagnosis of cases for registration is the difficulty of making a diagnosis in young children. For example, in setting up a register of children with congenital malformations some, such as pyloric stenosis, cleft lip and palate, anencephaly, spina bifida and talipes equinovarus, are easily recognizable at birth. In some cases congenital dislocation of the hip can be recognized early, in others the diagnosis cannot be made until about the child's first birthday. In some babies a congenital malformation of the heart may be recognized at birth but, despite sophisticated investigations, a correct anatomical diagnosis of the defect may only be possible at operation or autopsy.

Yet another difficulty to be taken into account in diagnosis is that of confounding, for example, acquired deaf-mutism with hereditary deaf-mutism due to a recessive gene; it is probably the latter which it is desired to register.

Usually the "best" diseases to register are those with single factor etiology, even if their severity is influenced by external factors. The latter must also be taken into account in analysing registry data. For example, when it is proposed to register a group of children at birth and to relate their growth and development to genetic factors and prenatal and postnatal influences it must be remembered that complications of pregnancy and delivery are specific to different economic and demographic groups.

As regards certainty of diagnosis, it is clear that in many instances the establishment of registers may be premature. In fact, this may be the weakest point in a registration system. Where it is felt that despite this drawback it is necessary to proceed, all the relevant factors must be taken into account, both in designing the registration system and in the analysis and interpretation of results.

2. What data should be recorded?

The golden rule here is to keep the data sheet as short and simple as possible. The objectives of a registry should be restricted at the outset, so that the data requirements are kept to a minimum; this will enable some practical results to be presented soon after the register's inception, and help to convince people of its usefulness.

It must be remembered that the purpose of a register is to answer some specific questions relating to a particular disease when the answers can only be obtained by registering and following up individual patients. The first essential is therefore to record sufficient basic data for each individual on the register to be infallibly identified. In some places this may mean only the patient's full name and date and place of birth, but where these are
confidential or where records are to be linked by computer, it may be necessary to devise an identification number composed of codes for several demographic and social characteristics.

For disease registers it is important, not only to register the diagnosis but also to record the means by which it was arrived at, e.g., the various laboratory or surgical procedures involved. For some diseases, such as cancer, it will be necessary to record the pathological findings and also the stage reached by the disease process at the time of registration.

What other data are collected will depend upon the questions being asked. Sometimes when an interesting piece of research into some aspect of the disease studied has just been published, it is felt that it would be useful to include in the registry data sheet some questions about these same aspects, so that the results can be compared with those previously obtained. Certainly there are often considerable advantages to be gained from replicating studies, but then there should be an exact and complete replication of the research in question, and this will not usually be achieved by putting some of the original questions into the registry data sheet.

It is best to include the relevant items of information for which accepted definitions already exist. For example, it is difficult to describe what is meant by "household" especially in transcultural studies but some standard definitions are usually provided for use in national population censuses. Where there is no standard definition for an item, an operational one must be included in the instruction manual, so as to ensure uniformity. Where registers are population-based, the national census office should be asked to provide sociodemographic data for the area covered, and the same items can be registered, so that eventually, incidence and prevalence rates can be produced for these variables.

It is also important to consider what are the possible sources of information and how reliable they may be. The patient is not always the most reliable informant, especially about social data. It is unwise to include in the data sheet items which can only be reliably ascertained by skilled interviewing unless the registry has the services of the requisite personnel.

In general it may be advisable to start by recording simple basic data from which statistics can readily be prepared, rather than to accumulate a mass of information which is difficult to handle and where many items may be intercorrelated. The first tabulations will usually show a number of differences for the explanation of which further items of information may have to be collected. These can be added to the basic data for a time, to be replaced by others when they have served their purpose. Similarly if new theories arise about the diseases in question, other questions to help elucidate them may be introduced into the registry data sheet. In this way a continuity in basic register statistics will be preserved, while a variety of additional questions can also be investigated.

3. How many cases?

Before setting up a disease register it is necessary to have some idea of the number of cases likely to be found. Some realistic assessment can then be made of the number of personnel required, the accommodation they will need, the amount of data to be handled, and the possible cost. Failure to take these factors into account may result in the registry being overwhelmed in paper; or at best the material will either not be analysed or the results will be too late to be of much interest.

Some estimates have been made of the number of cases which may require registration. For example, it was suggested that according to the experience of existing cancer registries, there would be between 150 and 300 new cases a year per 100 000 inhabitants, and that with annual follow-up the peak load would be reached in about seven to 10 years.1 The common

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congenital malformations mentioned in subsection 1 above all have frequencies of more than one per 1000 total births, and congenital malformations of the heart probably occur five to seven times per 1000 live births in Caucasian populations.

But rather a large number of births is required for establishing twin registers. For Caucasian populations a malformation with an incidence of one in 1000 births would occur in a twin once in about 40 000 total births. To collect information on 10 twin pairs of which at least one had the malformation, 400 000 births would have to be screened. Since only about one twin pair in three is monozygotic, for 10 monozygotic twin births, information on over 1 000 000 births is needed. The collection of such twin data would therefore need the combined effort of many hospitals over several years.1

It would be useful to know how many people who have diseases such as mumps or herpes zoster later develop cancer, but here again the question of numbers arises. One approach is to ask people who develop cancer whether or not they have had mumps. Many will not remember or will think they had mumps because they had swollen glands. There is also the problem of whether the mumps was complicated by orchitis or not. Recall in the case of herpes zoster is likely to be even less reliable than with mumps. This retrospective method will not, however, show the probability of developing cancer to which mumps or herpes patients may be subject. The better research strategy would be to register cases of mumps and herpes and follow them up, but in the first place it is not known how many cases would need to be registered and the question arises at the outset whether the results would be worth the effort involved.

Another difficulty in deciding how many cases to register is that over-zealous case-finding may result in the inclusion of too many false positives. In cancer registration in particular, the severity of the disease should be recorded because, if milder cases are included that can more easily be treated by surgical removal of the tumour, the survival rates will not be comparable with those where only more severe cases are included.

The question of follow-up usually receives less attention than it merits in proposals to establish disease registers. Either the number of cases recorded must be kept within the bounds of what it is possible to follow up, or sampling has to be undertaken. In consideration of the numbers with which a registry can cope, attention has also to be paid in deciding upon the original size of the registry, to the allowance that must be made for cases that will be lost at follow up.

4. "Who?" and "where?"

Consideration of the need for accurate diagnosis and of the possible size of registries naturally leads to the question of where they can be set up and who can run them. Two categories of personnel are required: those who will carry out the registration process and those whose task it will be to maintain the registries and exploit the data which they generate. Unless both types of personnel are available the register will tend to be inaccurate and not utilized to an extent which justifies its establishment in the first place.

Registers fall into two main categories - service-based and population-based. The former will be maintained by hospitals or public health organizations. In this case the patients registered will be those who come in contact with the service, e.g., hospital-based cancer registries or health service-based tuberculosis registers. Both of these facilities will have means for diagnosis and will be staffed by people who are interested in the future wellbeing of their patients for follow-up. Whether they will also have sufficient staff to maintain the registers is another matter. The situation may be worse with population-based registries. In the case of cancer, efficient registration will depend not only on the

collaboration of hospitals, but also on getting the cooperation of all private physicians in
reporting cases which come to them from the selected area. In addition, the death certificates
of all people from the area should be examined to see whether cancer was a primary or con-
tributory cause of death; this cannot be done where the death registration system is
imperfect. To ensure complete registration it will be necessary to record cases from the
chosen area who are admitted to hospitals outside that area, while patients resident outside
the area but admitted to hospitals or consulting doctors within the area must be eliminated.
The registered cases will then have to be checked to ensure that there is no double-counting.
Correcting the register by eliminating duplicate cases and removing cases subsequently found
not to have cancer involves a heavy load of work. This kind of work not only requires a
sufficient number of personnel, but also that they should possess certain inborn
qualities of patience and tenacity as well as an educational level which will enable them to
profit from the training which has to be given to registry staff. It is perhaps not
surprising that a WHO Expert Committee on Cancer Control, while agreeing that the function of
population-based cancer registries which has received most attention is that of finding the
incidence of the disease in relation to the form of cancer, and its distribution by sex, age,
urban or rural residence, occupation and other subgroups, and its variation over time, place,
personal characteristics, etc., nevertheless made the following observation:

"While it is generally conceded that the study of such variations may permit the
formation of hypotheses about causes, and may thus provide important leads in research
on the etiology of cancer, nowhere as yet has the potential value of cancer registry
material for this purpose been explored to any great extent. This is doubtless in
part due to the inadequate staffing of the majority of registries."1

It is apparent, therefore, that with the best will in the world, and with a full
appreciation of the advantages to be gained from such registers as those for cancer, many
developing countries just do not have the means either to establish registers or to analyse and
evaluate the material accumulated. Reference has already been made to a WHO consultant's
opinion in 1956 that cancer registration for all or even a substantial part of Egypt was
impracticable at that time, and later information is that it is still impossible outside a
few large towns.

However, even the economically developed countries may find it difficult to maintain and
exploit registers. Thus a WHO Expert Committee on Human Genetics stated:

"Chromosome analysis is recommended in all cases of: (a) suspected Down's syndrome;
(b) juvenile oligophrenia; (c) repeated spontaneous abortions, stillbirths and multiple
malformations; (d) sex-chromatin findings not consistent with phenotypic sex;
(e) exposure to mutagenic agents; and (f) infertility in males with normal phenotype.

The Committee realized that few, if any, laboratories could at present undertake
this large and costly programme. It was of the opinion, however, that under ideal
conditions all such cases should be karyotyped."2

Fortunately, the bacteriological diagnosis of tuberculosis is less difficult than
chromosome analysis, since the eradication of the disease in developing countries is going to
depend upon efficient registration with surveillance to see that medication is taken. Such
registries need to be situated at the local level, where the recipients of the service are
to be found. Not only is it easier for them to get their drugs, and for defaulters to be
detected but, as found in the case of rheumatic fever, there is considerable psychological
value in the personal handing over of a drug as opposed, for example, to its delivery by the

1 World Health Organization (1963) Cancer control, First report of an expert committee,
postal services. In general, registries involved with the provision of services or with the immediate examination of living or autopsy material are best situated at the local level. Other registries may have to be placed in large, well-developed research centres. Some may even have to serve more than one country and in particular to work on material provided, in preserved form, from developing countries; the problem and the means for solving it do not always occur in the same place.

Local registries, however, need to be coordinated from a central point, and in the case of tuberculosis registries it is an advantage to have staff from a central registry visit the local registries as they can then see that the service is functioning properly.

It may not be possible at the local level to provide statistical personnel to undertake the analysis of registry data, and a central data processing centre is advisable. However, some simple statistics can be routinely prepared at local levels as this helps to keep up interest in what is happening, and it is possible to interest administrators in what is being achieved. Where records are sent for central analysis, it is important that there should be speedy feedback of interesting material.

Registers will probably succeed best where they have the backing of the health authorities and this will be where these authorities have something to gain from the register. Automated registers, for example those based on routine admission and discharge data, will succeed where the level of statistical reporting in the hospitals is good. To ensure this it is essential that statisticians from the central registry see that people at the grass-roots level are trained in how to collect the data and fill in the records accurately. All workers must appreciate that their cooperation is invaluable for the success of the register and this can best be done by providing an end-product which is of recognizable value to them.

Another important problem in deciding where to set up a register is whether background sociodemographic data exist for the area chosen. These data are produced generally for census divisions or tracts, and it is as well for the area chosen for a population-based register to coincide with one or more census areas. Since population-based registers can best be used to obtain incidence and prevalence rates it is not only necessary to have the background census data for the total population so that rates can be calculated, but the registry data must be collected in the same units as those from the census, e.g., age, civil status, occupation and other groupings. Since the utilization of data from registers may involve other disciplines, such as demography, sociology and economics, it is useful to situate a central registry where close contact with those experienced in these subjects can be maintained.

Because of the need to follow up patients, a register may work more successfully in a town, where it is possible to send out health workers to trace and interview patients. This may happen especially where the questions to be asked are of a rather intimate kind, as with registers of patients who have had genetic counselling or who have been in mental hospitals. There is some reluctance to send questionnaires by post, in the first place because they may go astray and confidentiality may thus be destroyed, and secondly because the returns may be biased, for example, by the greater readiness to reply of people who have followed advice than of those who have not.

It is easier to carry out the follow-up required by a register if a link with the administrative machinery is available. For example, in countries with national health services, patients may be required to register with one physician. If they change their address a new registration card is issued and the old one returned to the area from which the patient moved, so that he can be taken off the previous doctor's list. These changes of address are noted in a central register and it is possible to contact the patient by letters passed through this registry. Statistics derived from a registry from which many cases are lost at follow-up can give very inadequate information. Several estimates of survival rates, for example, may have to be prepared, assuming (a) that all the missing patients are dead or (b) that they are all alive, or (c) that they have died at the same rate as similar patients in the general population.
5. When should a register be established?

The simplest answer to this question is: when the conditions described above for successful disease registers have been fulfilled. Where existing data from registration of births and deaths, from disease notification and from routine reporting is inaccurate and incomplete, it is unlikely that a disease register will be successfully established. The first need is to establish a good tradition of accurate basic reporting, and for this purpose special demonstration projects can be very helpful.

In view of the complexities of registers and their cost in terms of time, money and personnel, one may say that they should only be established when the required information cannot be obtained by other means, such as repeated cross-sectional studies of the population.

It should also be considered whether new cases should constantly be fed into a register, or whether it is possible to take in cases for two or three years, then work on the follow-up of registered patients for a few years, and afterwards take in more cases. In this way a more equal distribution of work can be achieved and the size of the registry can be limited. This system will work provided that there is little likelihood of any phenomenon in the type or course of the disease, or in methods of treatment, arising and disappearing in the time that cases are not being registered. There should be no hesitation about discontinuing a register when it has done what was required of it and this is especially true when services are being evaluated by means of registry data.

Finally, it may be said that a register can be set up when the results are not needed at short notice. In the case of cancer registries, it is necessary to follow patients throughout their life-span. For cases obtained from twin studies it may take several years to collect a sufficient number of subjects. It must be realized that for the most part registers supply long-term answers, and that the introduction of services cannot always wait for the results of registration and follow-up.

IV. DIFFICULTIES IN ESTABLISHING AND EXPLOITING REGISTERS

It may be thought that the discussion in the previous section has brought to light all the difficulties of registry maintenance. However, some have not yet been touched upon.

1. Connected with case-finding

A problem that occurs here is to what extent population screening should be used to find cases for registration. If mentally retarded people are being successfully cared for at home, there may be no need to search for and identify them. Some workers contend that population screening should not be carried out when a service cannot be offered to the patients identified.

The difficulty of establishing a register may vary in direct proportion to the number of sources which have to be examined in order to find cases. Registers of disabilities have so far made little progress, probably for this reason.

High-risk families can be identified only when more than one case, for example, of an abnormality occurs. However, a family may limit its reproductivity after the birth of an affected child, so that a second case may not appear and the family may not be detected. In registering patients with congenital malformations, the whole population should be covered, not just the maternity hospitals where births may be well documented. But even when all means of case-finding are used there may be some difficulty in relating back to the original groups of births in the defined population. It is necessary too that the frequency of occurrence in embryos and dead fetuses should be ascertained, as well as in spontaneous abortions. Lack of facilities and personnel may make the required examinations impossible.
It has already been stressed that there may be a lack of uniformity in diagnosis when information is collected from several sources, for example from death certificates of cases not treated in hospital as well as of those who were. Another problem arises when the method of diagnosis changes during the course of the life of a register. The later cases and their survival rates may then differ considerably from the life expectancy of earlier cohorts.

On the other hand, analysis of registry data may show that the disease itself has changed. For trachoma it has been established that in many areas, although the inception rate remains the same, the disease is becoming progressively milder. It is thought that the fact that the proportion of disabling sequelae in the later cases is lower than in the earlier ones indicates a change in severity and is not due to any marked improvement in the advice given to patients.

2. Connected with follow-up

Apart from the difficulties due to patients moving out of the area of registration there are others which are due to the local, social or cultural conditions. Thus it may be difficult to link up records because there are customary changes of name, other than those following marriage. In some countries there are areas with no addresses in the usual sense of this term, and certainly no telephone. In practically all, there are still people who are illiterate and so cannot read the letter telling them to attend for re-examination, yet their reading disability may make them more disease-prone because they do not understand what protective measures they should have undertaken in the first place.

The results of follow-up may be difficult to assess where patients migrate from one area into another where the medical services are better developed. However, it may be possible to use the migrants as a control group for assessing those left in the original area. Thus for schistosomiasis it is recommended that those on the register who move to areas where schistosomal infection is not endemic, where medical facilities are more extensive and where developed postal systems make follow-up less arduous, should be studied because they would provide information which can be used to assess the public health importance of this disease after transmission control schemes have been instituted. However, care must be taken in interpreting the data, because the patients' nutrition and general medical care may also have been improved.

Follow-up is a prospective operation, but in some registers it may be necessary to carry out a retrospective inquiry if the disease etiology is sought. This is so with some cancers where there may be a long delay between cause and effect. Clusters of deaths occurring in certain places may be one indication of the need for retrospective studies. It was by tracing back the previous history of those patients who were registered in the terminal phase of their illness that a number of carcinogenic industrial agents have been identified and eliminated or rendered harmless by protective countermeasures.

3. Connected with organization

There seems little doubt that some registers collapse under the weight of documents and information with which they cannot cope. When it comes to arranging the register there are several possibilities: for example the records may be assembled alphabetically, so that it is easier to identify and update the record with follow-up information; or they may be assembled by diagnosis for easy data-retrieval, which is all right if the diagnosis remains constant; or they may be arranged by date-of-birth, which is thought to be the easiest way for ensuring nonduplication of cases.

Where a register is to run for many years a means has to be found for clearing out the records of those who have been cured, have died or have emigrated. This means that a cure has to be defined for the disease in question. For psychiatric registers the definition of cure will involve a great deal of discussion. The removal from the register of patients who have died will be easiest if both the disease register and the national register of deaths are computerized and if there are the same identification data on both sets of records. There may, however, be no alternative but to make an inquiry for each patient whose condition at follow-up is unknown.
It will be seen from the foregoing that the difficulties facing those working in disease registries are daunting. Investigation of the work of cancer registries in the United States of America led to the conclusion that there was a lack of interest, cooperation and involvement on the part of the hospital medical staff; this was probably because the registry did not do its work properly. This in turn was due to inadequate guidance and assistance being given to registry personnel in their daily task. Quality control was inadequate; the work of registry staff should be checked regularly. There was not sufficient utilization of the data to audit the performance of medical officers in case management and to provide source material for professional and public education programmes. Matters were made worse by the non-availability and high turnover rate of secretarial and technical personnel. Mechanical and electronic equipment would have been helpful for processing and retrieving data, but the whole picture was overshadowed by the question of finding continuing financial support.1

A final difficulty is that when a register is set up, the data it will provide are intended to answer certain questions which are being asked at present. By the time the registry material has been collected and analysed, new questions may have arisen which the original data cannot answer. Thus the remark was made with reference to cancer registration - "the difficulty is that we are setting up the registry with today's knowledge but for tomorrow's use". It is a disaster when a register has to be reshaped.

V. HAVE REGISTERS DONE WHAT WAS REQUIRED OF THEM?

It may safely be said that some registers have succeeded in doing what they set out to do. Others have proved disappointing and have been abandoned. This may be due to the fact that their objectives were not clearly formulated at the start. In some cases a strong personality may keep a register alive and supply a lot of data, but no one can quite see how to use it. As registers are essentially long-term projects, in many cases it will be a considerable time before their value can be assessed. However, some lessons can be learned by those who are contemplating setting up registers.

Tuberculosis registers are among the oldest and in their purpose of facilitating surveillance, continuous treatment and prophylaxis some have been eminently successful. In Denmark, for instance, tuberculosis has been practically wiped out. However, in some developing countries success is only partial and there is a constant struggle to educate personnel, see that they carry out their tasks and try to get some statistics that will stimulate a little interest.

Rheumatic fever registers have also had considerable success in their avowed aims of preventing recurrences and decreasing the development of rheumatic heart disease. Here again success has been in developed countries. One would therefore expect phenylketonuria registers to succeed under the same circumstances. There may be some time to wait before an evaluation is available.

Cancer registration has already resulted in widening knowledge of the epidemiology of carcinoma of various sites and their connexion with occupation, dietary habits, air pollution, mineral content of the soil and other factors, to which the work of Dr Percy Stocks has largely contributed. The difficulty here is to get people to change their habits, as with smoking and lung cancer, when they are faced with the prospect of a disease which may take many years to develop, if indeed it ever does.

Some results of practical value have emerged from registers of maternities, with detailed obstetric records, in which the children have been periodically examined. Thus in the cohort study of 56 000 women referred to in section II, subsection 7, it was found that children with shorter intersib intervals scored lower on intelligence scales than those with longer intervals.

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and that there was also a difference in their birth weight, their eight-month development scores and the results of their neurological examination at one year.

While such a finding might lead to advice about spacing births which many would perhaps disregard, positive action was taken on the results of another study of 45,000 children examined at four years of age. These children were rated one minute after birth on five items, namely, heart rate, respiratory effort, muscle tone, reflex irritability and colour. They were rated 0, 1 or 2 on these items, the total of their subscores being known as the Apgar score. Infants who score 3 or less are severely asphyxiated. The score was taken again at five minutes after birth. Fetal distress was associated with a low fetal heart rate, meconium staining and one-minute and five-minute Apgar scores each less than or equal to 3. Results suggest that these conditions distinguish children with cerebral palsy from their controls. Since acute intrapartum haemorrhage is ultimately due to the effects of uterine contractions of labour, a new approach was now taken; the inhibition of the contractions to correct disturbances in fetal homeostasis and the postponement of delivery until the latter was normal. If this treatment does in fact reduce the incidence of cerebral palsy, it can be claimed that this particular register has done what was required of it.1

Registers formed by linking together all hospital admission and discharge documents for the same person can be used to answer questions about the utilization of services by individuals. They have the advantage of using the same data-sheet twice, for different purposes. Time is saved because no follow-up interviews are needed. It must be recognized that such registers do not answer questions about the patient's psychiatric state, his symptoms, work record or general adjustment. These registers are usually based on large numbers of patients, so that errors which occur may be compensatory. However, since the registers link up the records of individuals they provide person-statistics, unlike annual admission and discharge data, which yield event-statistics without reference to persons.

This type of register was used for patients admitted to psychiatric hospitals in England and Wales during the 1950s, when the policy of informal or voluntary, as opposed to certified (compulsory) admission was introduced. It was immediately claimed that under the new system patients would discharge themselves against advice before they were fit to leave, would then have to be readmitted, and thus a "revolving door" would be created. In 1954 a register was started of all new patients admitted in that year, and the follow-up was continued down to a fifth anniversary date in 1959. Similarly new cases in 1955 and 1956 were registered and followed up until a two-year anniversary date. When the readmission rates for the 1955 cohort were compared with those for the 1954 cohort, the rates for first and second readmissions were slightly higher, but there was little difference in the rates for third or subsequent readmissions. What was more important for the justification of the national policy was that the total percentage time spent in hospital by members of the 1955 cohort during the two years following admission was considerably less than for the 1954 cohort, so that patients were not away from the community longer, as had been predicted.2 A new Mental Health Act was introduced in 1959 and in 1964 another register was started for admissions in that year; these were followed up for five years until 1969. When the analysis of this cohort is available it will be possible to compare the experience of two admission cohorts, each observed for five years, one before the introduction of new legislation and the other after the working of the new Mental Health Act was established. These registers, which covered inpatient admissions for the whole country, were also used for other purposes: firstly, to assess, under certain conditions, the number of beds likely to be required for

mental patients; secondly, to test the working of the Act; thirdly, to identify for research purposes a series of patients with periodic psychoses by seeing at what intervals of time patients were admitted. A most useful service provided from the register was to tell individual psychiatrists whether their discharged patients had been readmitted and for how long; this was very helpful when new drugs were being tried out.

A more comprehensive register, covering all types of psychiatric services, was set up in a town of some 354,000 inhabitants.

Two agencies were concerned in the delivery of services when the register was set up, the local psychiatric hospital and the mental welfare department under the City Medical Officer of Health. The latter had a Mental Welfare Officer who controlled a staff of psychiatric social workers. The psychiatrists were based at the hospital and went out to make domiciliary visits and to take outpatient clinics as well as serving the inpatients. A day hospital existed within the hospital grounds and also a night hostel. The psychiatric social workers attached to the hospital worked jointly with those of the local authority.

A normal way of entering the services was to contact the Mental Welfare Officer who could make the decision to take no further action or to invoke the hospital services. Except in cases of emergency, one of the hospital psychiatrists would pay a domiciliary visit and decide whether the patient should be admitted to the outpatient or inpatient service or whether he should be referred back to his family doctor. The hospital was regarded as a pioneer establishment in the development of community psychiatry and as the organization of the services aroused considerable interest abroad, it was felt desirable that some statistical measure should be provided of what was being done. The number of inpatients had been running down from 1947 onwards, although in the whole of Great Britain this decrease did not start until 1955.

Several questions were asked. For example, how many and what sort of patients were maintained by the extramural services without becoming inpatients, and did the total treatment spells show the same distribution in terms of days of care as those for hospitals where a more conservative type of service was being given consisting of inpatient treatment and outpatient after-care, or did the effect of using several services make the total treatment spells longer? Another question was whether the service was carrying patients who were chronic in the sense of always being in one type of service or another, although they were not chronic in the former sense of being continuously hospitalized.

A register was therefore set up and all documents relating to the admission and discharge of patients or to domiciliary visits by psychiatrists and social workers were fed into a central office. Here the data for each person were assembled to show the dates covered and the items of care delivered for treatment spells - a spell being defined as the period from the date of first contact for any episode of illness until a member of one of the services stated that no further action was required. It was proposed to examine the treatment spells for yearly and two-yearly periods from the date of contact for each person, so that each was followed up for one, two, or more years. It should be emphasized that since the register was concerned solely with the examination of the care given, there was no question of case-finding or of incidence and prevalence of mental disorders. Nor was it concerned with a number of units of service given to an unknown number of persons in a given population, since this information can be obtained from annual admission and discharge data without having recourse to a register. It was primarily concerned with answering questions about what happened to individuals and how the service components of their spells of treatment changed over time. This register has not yet been exploited in the way which was originally intended and so has not yielded answers to the questions which led to its establishment. It will, however, serve as a model for registers to be established in the pilot study areas which are being set up by the European Regional Office of WHO in relation to the long-term plan for psychiatric services. By turning event-statistics (of admissions, discharges, visits to outpatient clinics, attendances at day hospitals, etc.) into person-statistics (what services are given to each
individual and with what outcome) it will be possible to make comparative evaluations of the services in the pilot study areas, which can serve as guides for other centres wishing to carry out the same tasks.

There is one danger in using psychiatric registers to measure the effects of the services and to assess future needs; it is not possible to assess overall national averages from the results of local registers. Where calculations are based on utilization of beds, a hospital which discharges patients more slowly than the average, or cannot rehabilitate its long-stay patients at the average rate, will give the impression that more accommodation is needed than is actually the case. Probably the best way to use local registers is to compare their results over time and relate the answers to changes occurring within the locality.

It may be concluded that some registers are fulfilling their functions. It is also probable that the methodology of using registers, for example for quality control, has not been completely developed. It is certain that registers will be more efficient when based on better records, and when the analysis is related to the purpose for which they were established.

VI. SETTING UP A REGISTER, WITH ILLUSTRATIONS FROM WHO/IHD REGISTERS

It is proposed to discuss the methodology for instituting a register and to illustrate the various steps from the development of ischaemic heart disease (IHD) registers which was undertaken by the WHO Regional Office for Europe with the help and support of headquarters. In the light of what has been stated in Sections III and IV, it will be seen that arrangements have been made to overcome the difficulties inherent in registers and to ensure the production of valuable data. This methodology can, of course, be adapted to a number of other diseases, as well as being extended to other cardiovascular and cerebrovascular disorders.

1. Examination of reasons for setting up the registers

In intensifying WHO’s work in the control of cardiovascular diseases, the establishment of ischaemic heart disease (IHD) registers was a key project. The programme described here included the collection of more and better information on IHD in the community, new developments in its prevention and treatment, and on the rehabilitation and follow-up of patients. It was also necessary to have programmes for the health education of the public and for training personnel. To study and evaluate the operation of the services, reliable data on follow-up, such as would ideally be obtained from a register, were essential.

2. Proposed method of operation

Work on the main projects in the programmes, from registration to evaluation of care and rehabilitation of coronary patients, were first to be concentrated in selected pilot areas. On the basis of the experience gained, the programme could later be extended to other areas. In this way, centres judged to satisfy the requirements detailed in Section III above, would be selected and at least some successful results would be assured.

3. Collection and examination of existing data

A European Regional Working Group of WHO met in 1968 and examined current knowledge of "heart attacks" and their treatment under five headings:

(i) Epidemiological data on "heart attacks"

Information was quoted from several studies which showed the high proportion of patients who died within a few hours of the attack.

(a) Two hundred and twenty-nine men and women aged 30-59 who at entry to the study were free of manifest IHD and developed a first "heart attack" during the study; of these 20% died within one hour, 4% at home without reaching hospital, and 10% in hospital.
(b) Pooled data for 566 men who developed "heart attacks": 25% died in the first three hours, 20% between three hours after onset and one year.

(c) A random sample of death certificates for people aged 40-64, with diagnosis of arteriosclerotic heart disease: of all deaths 72% occurred within 24 hours from the onset of symptoms.

From these and similar studies it was deduced that control programmes must be based on detailed information about the occurrence of "heart attacks" of the kind which registers can supply on a continuing basis.

(ii) Coronary treatment services

While it was known that special coronary care units could reduce both mortality and subsequent disability, the exact role of such units and under what circumstances they should be provided was not yet apparent. Registers would point to weak areas in the provision of treatment and help to make the development of special care units more economical.

(iii) Pathological diagnosis in early deaths from acute IHD

The method of diagnosis, especially in the case of early deaths, was not completely clear. Arrangements were therefore made for a special meeting of pathologists who would be working on the registers so that they could produce agreed minimum criteria for:
(a) the presence of IHD; (b) the fact that it had caused the death in question;
(c) the presence of chronic IHD; and (d) whether other heart disease had caused death.

In this way it was hoped to ensure the certainty and uniformity of diagnosis which registers require.

(iv) Experience from a previous register

The one quoted was a one-year study of acute coronary disease in Edinburgh. The methodology of case-finding, examination of patients, and keeping up enthusiasm among the staff was described. An estimate was also made of staffing in relation to the population covered.

(v) Continuous supervision of coronary patients

Information was provided about the registration and continuous supervision, for one year after the attack, of patients with acute myocardial infarction and the long-term therapy provided for them in many larger cities of the USSR.

4. Statement of what the register was expected to do

(i) Provide measures of the local need for services and information about whether the existing services were adequate for their tasks.

(ii) Provide a basis for the evaluation of old and new methods of management by comparing the results for groups managed in different ways.

(iii) Provide a more complete clinical picture of the natural history of the disease than can be got from hospital cases, help in the study of etiology and pathogenesis and thus reduce the large number of fatal cases which occur soon after the attack.

(iv) Help in research - clinical, epidemiological and bio-engineering - by providing representative cases for study, a sampling frame for clinical trials and by relating all findings to the total community problem.
5. Need for education

It was realized that a considerable effort would have to be made to educate both public and professional people if the registers were to succeed, since at present there are many countries where little attempt is made to establish the cause of "sudden deaths" other than those due to violence.

6. Statement of the minimum operating protocol for the pilot scheme

The requirements for notification of patients and the data to be collected for the register were clearly set out for the IHD registers as follows:

(i) who should be notified;
(ii) diagnostic criteria for notified patients;
(iii) provisional classification of notified patients;
(iv) estimation of the severity of the attack;
(v) minimum background information:
   (a) sociodemographic;
   (b) previous medical history;
(vi) intervals at which follow-up should be done and the information to be collected;
(vii) instructions for obtaining complete notification;
(viii) instructions for checking notification and registration.

7. Criteria for selection of pilot areas

To give the pilot registers a good chance to succeed, areas were only to be selected if they satisfied the following criteria:

(i) presence of epidemiological and cardiological skills, interest and enthusiasm for the task, and the necessary resources to organize a suitable study team;
(ii) medical services which would bring all people with heart attacks to notice and would provide full treatment facilities;
(iii) full cooperation of most hospital and non-hospital doctors;
(iv) the study population to be that of a defined administrative area for which adequate and recent demographic and social data were available, and to be large enough to yield a minimum of about 200 "heart attacks" in a year.

8. Personnel

It was realized that, for each of the pilot areas, a principal investigator should be appointed who would be responsible for the work of the registry and for coordinating the efforts of local participants.
9. Review of initial experience

Twelve centres in Europe started registers between August 1969 and July 1970 and four others made preparations to start.¹ A review meeting was held in Copenhagen in mid-1970. Although some amendments to the record forms were suggested, it was decided not to make any changes during the course of the study. However, nearly 40 amendments or extended explanations were made in the text of the operating protocol to make it more specific and avoid ambiguities. Additional methods for checking the completeness of registration were proposed.

10. Arrangements for data analysis

From the very beginning of the project professional statisticians were involved in the design of records, methods of completion and arrangements for producing the type of data required to serve the purposes for which the registers were established. As a result, data analysis could begin immediately after the collection of material. The result was that all record forms sent to Genova before 15 February 1971 could be included in the statistics prepared for the meeting of the Working Group held in April 1971. One of the worst difficulties of registers, that of a vast amount of data which cannot be quickly analysed, was thus avoided.

11. Sequel

It is proposed to develop other disease registers in a similar way and a complete programme has already been drawn up for the institution of "Stroke" registers in relation to a programme for the control of stroke and hypertension in the community. A first scrutiny of the tabulations for the IHD material suggests that many of the aims of this register have been achieved, which is in itself an encouragement to continue with other forms of cardiovascular disease.

VII. POPULATION MORBIDITY REGISTERS

A disease register is devoted to one disease only, the statistical event recorded being the occurrence of the disease in a particular patient. In cancer registration, if a person has cancers of two sites, the two cancers will be registered separately, although in some cases they may be cross-referenced. The same person, if he has several registrable diseases, will appear in a number of different registers and the connexion between his maladies will not be brought to light. An alternative to the registration of diseases is the registration of persons who will then be described in terms of all the illnesses or accidents they suffer over defined periods of time, with their order of occurrence and the intervals between them. The longitudinal studies of persons, which are the essential ways of utilizing registers, will enable the patterns of total morbidity in individuals to be studied; significant associations between types of illness may thus be discovered, which would be highly relevant for etiological studies.

Such a register, which shows the whole morbid history of each individual, is regarded by many workers as most desirable. Like disease registers, it could show the incidence rates of diseases in the population group chosen for study. It would have the advantage of being able to show whether diseases are distributed randomly over the population, or whether a rather limited number of people account between them for the greater part of the total population morbidity. If the latter were true there might be as much advantage to be gained from studying the entirely healthy as the sick sections of the population, since the incidence of health is not widely studied or assessed.

¹ They were in Boulogne, Bucharest, Budapest, Copenhagen, Dublin, Göteborg, Heidelberg, Helsinki, Innsbruck, Kaunas, London, Dublin, Nijmegen, Prague, Tampere and Warsaw.
Morbidity registers are useful for evaluating the medical services, which for the most part are geared to promoting health and preventing long periods of incapacity. They are useful for estimating the total cost of chronic disease and how it varies from place to place and over time. Efforts to obtain such information have been made, mostly in the form of surveys of sickness in sample populations. The difficulty about trying to estimate the duration of incapacity retrospectively by interviewing is that the length of recall varies greatly from person to person. Many people do not know their diagnosis and to verify what they report either by checking up among their doctor's records or by medically examining a sample of patients is usually too expensive to be undertaken. To yield valid information, prospective studies must be carried out.

In the past it has often been difficult to ensure complete reporting because information had to be obtained from many sources, whose reliability could not always be established. For example, it has been almost impossible to add the total of laboratory tests, medication prescribed and social services provided. However, it is more feasible to build up total morbidity registers today, under suitable circumstances. One of these is the existence of a universal insurance scheme, whether public or private. Where insurance requires a patient to adhere to the services of one doctor or one group practice only, the practice records can be used to build up a morbidity register for his group of patients. When specialist services are required he will invoke them, whether they are consultant, X-ray or other examinations. He will also know when patients are hospitalized and any operative procedures they undergo. The chief difficulty of basing a register on a practice population will be that the basic sociodemographic characteristics of the total patients registered with the doctor will not be known, although as a research project it should be possible to get some simple basic data on which morbidity rates for the practice population can be calculated.

Another method of building up a prospective morbidity register is to take the personnel of a large industrial enterprise as the study population. This will generally provide a cross-sectional variation in sex, age, marital status, education level, area of residence and type of work in the organization's personnel. Here the register may be built up by record linkage, since in most large companies sickness certificates are required for absences of more than a few days. In the British Civil Service, studies of absence due to sickness have been based on doctors' certificates. Since a medical certificate is required when a worker is away for more than three days consecutively and since not more than a total of seven days of uncertificated sick leave is allowed in 12 months, starting from the first day of any absence, considerable accuracy has been achieved. In fact, this system ensures that most illnesses, even of a minor nature, will be recorded in the individual's service file.

Since it may be claimed that such closed groups as have been mentioned are specially selected because admission to them requires the passing of a medical examination, it may be pointed out that when this population is ill, there is no reason to suppose that the sequence of diseases is different from that in the rest of the population. However, better results may be obtained where an organization itself provides a medical service for its employees and their families. In this case it is possible to make longitudinal studies not only of individuals and their registered diseases but also of the patterns of disease in members of the same family.

VIII. CONCLUSIONS

It is important to recall at this stage what a register is, namely a list of individuals who at a specified point of time develop the disease which is the basis of the register. The register must be constantly updated by recording the changes which happen to these individuals and the dates at which they occur. New cases will be added to the register and others will be deleted when the patient recovers or dies. As this is likely to be a time-consuming and complicated process it follows that a register should only be set up when there are questions to answer and the necessary data cannot be obtained by any other means. Replies to the questionnaire sent out by WHO with the first draft of this report show that difficulties are minimal where the reporting system is limited to hospitals only or to a
disease of low incidence (such as hereditary bleeding disorders) or which is compulsorily notifiable (such as enteric fever). As soon as the sources of information multiply, so do the difficulties, as for example with a register of mental handicap where the data have to be collected from both hospitals and local authority health services whose record systems are organized in different ways. Under-reporting - due to the difficulty of obtaining cooperation from sources other than public health hospitals - and follow-up difficulties - due to the problem of ensuring that the register receives information on deaths and migration among people outside hospital - may also be encountered.

On the other hand, success may add to the problems, as for example: "The register has been recognized by hospital psychiatrists as a very valuable tool. Inability to supply all data requested by hospitals because of other commitments is a recurring problem" (New Zealand). Or with regard to the Cancer Registry for England and Wales: "The efficiency of cancer registration varies considerably and coverage, to a degree, is related to efficiency ... Over many years coverage has gradually increased and our current 148 000 new cases each year represents an average coverage of some 90%. It is becoming increasingly difficult to maintain this coverage owing to the expense and consequent shortage of records staff in hospitals and regions. In some areas where money is available it is difficult to find staff of sufficient calibre to carry out medical records work in general."

Hence, while disease registers can and often do serve a useful purpose, considerable caution should be exercised in deciding to set one up. Most medical services want to show that they are working well and they have more to gain from successfully operating a service-based registry, as for tuberculosis and rheumatic fever, than from a research register of chromosomal anomalies.

Reports from the countries show there is a fundamental need to improve basic statistical reporting. Much has already been done for reporting causes of death, but the field of morbidity reporting is relatively untouched. The analysis of morbidity data from a number of centres is not only likely to show that a high proportion of items is left blank, but also that there are obvious incompatibilities between data recorded in different parts of a data-sheet. Thus so far as diabetes mellitus is concerned, the collection of detailed data requires the participation of a well-developed health service, a specialized endocrinological service and a single school of endocrinology. Doctors should receive detailed instructions on how to fill in the cards (Bulgaria).

Probably many workers do not sufficiently appreciate the potential value of what they are doing, and personal communication is essential. From the Salford Psychiatric Register (United Kingdom): "You absolutely need a highly committed rather obsessional approach by all register personnel. It is difficult to develop or maintain reliable collection of data without personal contact with all the relevant service agencies especially if they are changing in any way. It is a great advantage for the one developing a register to know the local situation intimately." The grass-roots workers must be sufficiently involved in the undertaking, and for this two things are especially important. The first is that the registry director should be prepared to go and sit down with the registry staff, observe their work, solicit their opinions and show them the ultimate importance of what they are doing. The second is that there should be a quick feedback of useful statistics to all who have taken part.

Where it has been finally decided that a register is necessary, there may be an advantage in carrying out a pilot study in several areas at one, as in the case of the IHD registers already described. Not only will each centre benefit from the others' experience, but the more hesitant will be encouraged to start, and all will be more likely to keep to a common time-schedule and therefore to obtain some results within a reasonable time from the inception of the register. Where several centres participate, uniformity of diagnosis can be enhanced by circulating typical case histories for diagnosis or using audio- and video-taped interviews with patients, followed by examination of agreements in diagnosing and recording.
Not only is it necessary to have preliminary training for those who will work in a registry, but this should be repeated from time to time. Otherwise some idiosyncratic interpretations of instructions may insert themselves, which will affect the quality of the data collected and which it will be difficult to eradicate. The development of manuals with information on establishing and maintaining registers and producing statistics from them is vitally necessary. In particular, reports on registry data should describe the statistical methodology used and also indicate to which diseases this does not apply.

If rather more caution is used in the future than in the past in setting up disease registers, they can form an important and useful part of medical information systems.
## APPENDIX 1

### DISEASE REGISTERS IN COUNTRIES THAT REPLIED TO A WHO QUESTIONNAIRE

#### A. INFORMATION ON REGISTERS CURRENTLY MAINTAINED

<table>
<thead>
<tr>
<th>Country</th>
<th>Diseases registered</th>
<th>Area/population covered</th>
<th>Year begun</th>
<th>Total registered</th>
<th>New registrations per year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bulgaria</td>
<td>Diabetes mellitus, Malignant neoplasms, Psychiatric disorders, Skin diseases, Tuberculosis</td>
<td>Whole country (8 600 000)</td>
<td>1968</td>
<td>40 000</td>
<td>4 000</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Whole country (8 400 000)</td>
<td>1952</td>
<td>79 075</td>
<td>15 147 (1971)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Whole country (4 000 000)</td>
<td>1952</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Whole country (8 400 000)</td>
<td>1961</td>
<td>260 000</td>
<td>8-10 000</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Whole country (8 400 000)</td>
<td></td>
<td>50 000</td>
<td>6 246 new (1971)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>24 130 old (1971)</td>
</tr>
<tr>
<td>Denmark</td>
<td>Acute myocardial infarction, Cancer, Sarcoïdosis, Tuberculosis</td>
<td>Copenhagen metropolitan, Denmark (5 million), Denmark (5 million), Greenland (30 000)</td>
<td>1972</td>
<td>1 000</td>
<td>4 000</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Copenhagen metropolitan</td>
<td>1942</td>
<td>400 000</td>
<td>16 000</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Copenhagen metropolitan</td>
<td>1962</td>
<td>5 500</td>
<td>250</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Copenhagen metropolitan</td>
<td>1921</td>
<td>67 000</td>
<td>900</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Copenhagen metropolitan</td>
<td>1955</td>
<td>6 000</td>
<td>100</td>
</tr>
<tr>
<td>Iran</td>
<td>Cancer</td>
<td>Isfahan region</td>
<td>Project for 1973</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New Guinea</td>
<td>Communicable diseases and all hospitalized diseases</td>
<td>Whole country (2.5 million), but sampling techniques used</td>
<td>1958-59</td>
<td></td>
<td>50 000 (number of persons not known)</td>
</tr>
<tr>
<td>New Zealand</td>
<td>Blindness</td>
<td>Whole country (2 862 631 in 1971) (retrospective)</td>
<td>1969</td>
<td>9 000</td>
<td>1 500</td>
</tr>
<tr>
<td></td>
<td>Cancer</td>
<td>Whole country (2 862 631 in 1971)</td>
<td>1948</td>
<td>98 000</td>
<td>6 000</td>
</tr>
<tr>
<td></td>
<td>Drug dependency</td>
<td>Whole country (2 862 631 in 1971)</td>
<td>1969</td>
<td>140</td>
<td>Not yet known</td>
</tr>
<tr>
<td></td>
<td>Enteric fever</td>
<td>Whole country (2 862 631 in 1971)</td>
<td>1959</td>
<td>504</td>
<td>25</td>
</tr>
<tr>
<td></td>
<td>Typhoid fever</td>
<td>Whole country (2 862 631 in 1971)</td>
<td>1947</td>
<td>2 000</td>
<td>40</td>
</tr>
<tr>
<td></td>
<td>Multiple sclerosis</td>
<td>Whole country (2 862 631 in 1971)</td>
<td>1954</td>
<td>1 384</td>
<td>95</td>
</tr>
<tr>
<td></td>
<td>Psychiatric disorders</td>
<td>Whole country (2 862 631 in 1971)</td>
<td>1966</td>
<td>40 400</td>
<td>4 500</td>
</tr>
<tr>
<td></td>
<td>Tuberculosis</td>
<td>Whole country (2 862 631 in 1971)</td>
<td>1949</td>
<td>6 000</td>
<td>700</td>
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<tr>
<td>Uganda</td>
<td>Infectious diseases</td>
<td>Inpatients of hospital (Kampala)</td>
<td>1963</td>
<td>2 160</td>
<td>240</td>
</tr>
<tr>
<td></td>
<td>Leprosy</td>
<td>Inpatients and outpatients (Kampala)</td>
<td>1967</td>
<td>643</td>
<td>150</td>
</tr>
<tr>
<td></td>
<td>Malignant neoplasms</td>
<td>Hospital Inpatients (Kampala)</td>
<td>1952</td>
<td>23 000</td>
<td>2 000</td>
</tr>
<tr>
<td></td>
<td>Tuberculosis</td>
<td>TB Control Centre (Kampala)</td>
<td>1972</td>
<td>50 000</td>
<td>5 000-0 6 000</td>
</tr>
<tr>
<td></td>
<td>Also registered:</td>
<td>All inpatients of Mulago Hospital (Kampala)</td>
<td>1951</td>
<td>1 200 000</td>
<td>60 000</td>
</tr>
<tr>
<td></td>
<td>Hospital inpatients</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Population register</td>
<td>Kasangati 12 000</td>
<td>1962</td>
<td>12 000</td>
<td>400-500</td>
</tr>
<tr>
<td></td>
<td>Health personnel register</td>
<td>-</td>
<td>1963</td>
<td>5 260</td>
<td>200-300</td>
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<tr>
<td>United Kingdom of Great Britain and Northern Ireland</td>
<td>Cancer</td>
<td>Whole country (50 000 000)</td>
<td>1945</td>
<td>2 300 000</td>
<td>150 000</td>
</tr>
<tr>
<td>England and Wales</td>
<td>Mental handicap</td>
<td>Wessex Hospital, region (5 million)</td>
<td>1963</td>
<td>10 000</td>
<td>300</td>
</tr>
<tr>
<td></td>
<td>Mental illness</td>
<td>Nottingham (400 000)</td>
<td>1964</td>
<td>-</td>
<td>-</td>
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<tr>
<td></td>
<td>Mental illness and handicap</td>
<td>Salford (140 000 in 1968)</td>
<td>1968</td>
<td>4 500</td>
<td>1 000</td>
</tr>
<tr>
<td></td>
<td>Mental illness and handicap</td>
<td>Camberwell (170 000)</td>
<td>1964</td>
<td>14 000</td>
<td>1 500</td>
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<tr>
<td>Northern Ireland</td>
<td>Hereditary bleeding diseases</td>
<td>Whole country (includes temporary foreign residents)</td>
<td>1954</td>
<td>126</td>
<td>Usually 4-5</td>
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<tr>
<td>Scotland</td>
<td>Cancer</td>
<td>Scotland (5 million)</td>
<td>1959</td>
<td>69 117</td>
<td>15 000</td>
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<tr>
<td></td>
<td>Psychiatric disorders</td>
<td>North-east Scotland</td>
<td>1963</td>
<td>13 500 (live, Feb. 1973)</td>
<td>2 300</td>
</tr>
<tr>
<td>United States of America</td>
<td>Psychiatric disorders</td>
<td>Maryland</td>
<td>1961</td>
<td>60 877</td>
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<tr>
<td></td>
<td>Trauma</td>
<td>Illinois</td>
<td>1969</td>
<td>4 811</td>
<td>-</td>
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### B. PURPOSES THAT REGISTERS WERE INTENDED TO SERVE

<table>
<thead>
<tr>
<th>Country</th>
<th>Disease registered</th>
<th>Estimate of annual incidence</th>
<th>Estimate of joint or period prevalence</th>
<th>Follow-up studies</th>
<th>Evaluation of various therapies</th>
<th>Forecast of future requirements (surgeons, beds)</th>
<th>Maintenance of therapy</th>
<th>Other</th>
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<tbody>
<tr>
<td>Bulgaria</td>
<td>Diabetes mellitus</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>Malignant neoplasms</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>Psychiatric disorders</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Study of changes in epidemiological indices; TB control planning</td>
</tr>
<tr>
<td></td>
<td>Skin diseases</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Tuberculosis</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>Denmark</td>
<td>Acute myocardial infarction</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Epidemiological research</td>
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<td></td>
<td>Cancer</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Epidemiology</td>
</tr>
<tr>
<td></td>
<td>Sarcoïdosis</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Epidemiological research</td>
</tr>
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<td></td>
<td>Tuberculosis</td>
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<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td></td>
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<tr>
<td>New Guinea</td>
<td>Communicable</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>diseases and all hospitalized disease</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td></td>
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<td>Blindness</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Provision of facilities for the blind at home</td>
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<tr>
<td></td>
<td>Cancer</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Effective means of health education</td>
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<td></td>
<td>Drug dependency</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Enteric fever</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
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<td>No</td>
<td>No</td>
<td>Supply of data for health education of farmers</td>
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<td></td>
<td>Hydatidosis</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Supply of administrative data</td>
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<td>Multiple sclerosis</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Definition of epidemiological groups</td>
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<td></td>
<td>Psychiatric disorders</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Supply of epidemiological data to Public Health Division of Ministry</td>
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<td></td>
<td>Tuberculosis</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
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<td>No</td>
<td></td>
</tr>
<tr>
<td>Uganda</td>
<td>Infectious diseases</td>
<td>-</td>
<td>-</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>-</td>
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<td></td>
<td>Leprosy</td>
<td>-</td>
<td>-</td>
<td>Yes</td>
<td>-</td>
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<td>-</td>
<td>-</td>
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<tr>
<td></td>
<td>Malignant neoplasms</td>
<td>-</td>
<td>-</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>Tuberculosis</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>-</td>
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<tr>
<td></td>
<td>Also registered:</td>
<td>Hospital inpatients</td>
<td>-</td>
<td>-</td>
<td>Yes</td>
<td>Yes</td>
<td>-</td>
<td>-</td>
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<td></td>
<td>Population register (basic health services)</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>-</td>
<td>-</td>
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<td></td>
<td>Health personnel register</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>Yes</td>
<td></td>
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<tr>
<td>United Kingdom of Great Britain and Northern Ireland</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>England and Wales</td>
<td>Cancer</td>
<td>Yes</td>
<td>No</td>
<td>-</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Feedback to cancer bureaux</td>
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<td></td>
<td>Mental handicap</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Etiological studies</td>
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<tr>
<td></td>
<td>Mental illness (Nottingham)</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Sampling frame for evaluation of services</td>
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</table>
### B. PURPOSES THAT REGISTERS WERE INTENDED TO SERVE (continued)

<table>
<thead>
<tr>
<th>Country</th>
<th>Disease registered</th>
<th>Purposes to be served</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>England and</td>
<td>Mental illness and</td>
<td>Estimate of point or period prevalence Follow-up studies Evaluation of various therapies</td>
<td>Monitoring of community services Planning and monitoring of patients' specific history and medical details</td>
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<td>Wales (continued)</td>
<td>handicap (Salford)</td>
<td>Yes Yes Yes No Yes</td>
<td>provision of sampling frame for research workers</td>
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<tr>
<td></td>
<td>Mental illness and</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>handicap (Camberwell)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Northern</td>
<td>Hereditary bleeding</td>
<td>Estimate of point or period prevalence Follow-up studies Evaluation of various therapies</td>
<td>Reference library of patients' specific history and medical details</td>
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<td>Ireland</td>
<td>disorders</td>
<td>Yes No Yes No No</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(haemophilia, Christmas disease, etc.)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Scotland</td>
<td>Cancer Psychiatric</td>
<td>Estimate of point or period prevalence Follow-up studies Evaluation of various therapies</td>
<td></td>
</tr>
<tr>
<td></td>
<td>disorders</td>
<td>Yes Yes Yes - Yes</td>
<td></td>
</tr>
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</tr>
</tbody>
</table>
FORM FOR ROUTINE BLOOD TESTING FOR PHENYLKETONURIA

This card to be completed in ordinary pencil only

Originating institution:
Address:
Name of doctor:
Date of collection:

Information on the child
Surname and first names:
Sex: Date of birth:
Birth weight: premature at term
Address:

For laboratory use only
No:
No:

PKU Case Detection Centre
Laboratoire Evian-Jacquemaire
Boîte Postale 303
74-EVIAN-LES-BAINS

Envelope
### INSTRUCTIONS FOR SAMPLING

1. After cleaning the skin with ether, puncture the heel or finger-tip of the child with the vaccinostyle included in the sampling kit.

2. Use a **SHARP CLEAN** stroke so that the blood will form well-defined drops.

3. Transfer the blood to the circles; each circle should be **filled completely in a single operation**.

4. Allow to dry in the air.

5. **TREATMENT IN PROGRESS**: Specify, since some drugs may affect test results.

### RESULTS:

- Chromatography:
- Guthrie: normal, doubtful, abnormal
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