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NATIONAL HEALTH SURVEY SYSTEMS in the EUROPEAN ECONOMIC COMMUNITY

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NATIONAL HEALTH SURVEY SYSTEMS in the EUROPEAN ECONOMIC COMMUNITY

Edited by

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Introduction

The papers published in this volume were prepared for a workshop conference on National Health Survey Systems in the European Community held in Brussels in October 1975. The conference was sponsored by the Commission of the European Communities, at the request of a scientific committee whose aim is to foster collaborative work in epidemiology, medical statistics and allied fields in the European Community. The purpose of the conference was to discuss ways in which the nine countries of the Community, and perhaps other countries, might cooperate in the development of national health survey systems.

The need for more extensive, and more reliable, health statistics is widely recognised by those concerned with health planning, health services research, and epidemiological studies. Every developed country has a core of vital statistics stemming from the statutory registration of births, deaths, and marriages. To a lesser extent, and less reliably, data may be available describing the utilization of the health services. But only fragmentary information is likely to be available about the general health of the whole population. This outline sketch may be filled in by special surveys dealing with a particular disease or disability, or with a particular sub-group of the population. Some countries though, have developed, and maintained for several decades, systems of repeated surveys covering virtually the whole population, although of necessity the information collected is limited. Because of the magnitude of such an enterprise, these surveys are almost inevitably carried out on a sub-section of the population selected by a statistical method which ensures random sampling. The information sought may be obtained either direct from the members of the population (health interview surveys), or by physical examinations or technical measurements (health examination surveys).

Health interview and examination surveys were the main topic of the conference, and of the papers reproduced here. It was, however, convenient to extend the scope of the meeting to include other forms of health information, particularly where the data might well be collected by sample surveys: hospital discharge records and records of primary care are two such examples. The aim in these papers is to avoid technical detail as far as possible; for example, there is very little reference here to the details of sample design or to methods of analysing data. The main emphasis is on the sort of information to which survey methods might be applied, on the practical problems of conducting national health surveys, and on the uses that can be made of the information collected.

The report of the conference is reproduced, with minor changes, as Paper 1, and may be read as a further introduction to this volume. The general recommendation of the conference was that continuing efforts should be made to prepare for collaborative health surveys in the countries of the Community. This recommendation has been acted upon and a working party has been formed which, it is hoped, will formulate plans leading to this sort of cooperation.

The succeeding chapters present detailed discussions of specific aspects of national health surveys. Paper 2 gives some indication of the interest of the Commission in epidemiology and health statistics, and the ways in which these subjects are being promoted by its various agencies and committees. Paper 3 attempts to set the scene against which the subsequent chapters should be considered, by reviewing the present state of health information and possible ways in which systems might develop. Papers 4-11 take up the story from the point of view of the various countries in the Community. Some countries have had more experience than others in continuous health surveys, and are able to report particular features of their systems in some detail; other countries outline the background from which future developments may be expected to take place. The next two chapters widen the discussion beyond the Community. Paper 12 explains the role of the World Health Organization in promoting health surveys, and outlines developments in certain countries outside the Community which are specifically referred to in other chapters. Paper 13 describes the national health survey system in the USA, which is the most extensive and long-standing example of these methods. This paper concentrates on the health interview surveys, leaving the health examination surveys to be covered in Paper 15.

The remaining chapters deal with rather more general aspects of health survey systems although they give further details about national systems which are particularly familiar to their authors. Paper 14 discusses the use of surveys as a tool for carrying out research within the health information system: it concentrates particularly on the problems of health interview surveys, and thus balances the discussion of health examination surveys in Paper 15. Many of the later chapters raise questions which are not completely solved and which must be borne in mind and discussed by those who plan such systems. To what extent are continuing survey systems preferable to *ad hoc* enquiries (Paper 16)? How can the information derived from continuous health surveys be used in health service planning (Paper 17); to develop health indicators (Paper 18); or in epidemiological research (Chapter 19)? Finally (Paper 20), how does the economist approach the problems of health planning, and to what extent can the provision of health information (and health surveys in particular) be justified on economic grounds?

The development of national health survey systems is in a transitional stage. Some countries have gained a great deal of experience over many years; others have yet to start. Both groups have much to gain by collaboration. It is hoped that the Brussels conference, and the present volume of papers, will play some part in fostering this international cooperation.

I should like to thank the participants at the conference, listed on pp. ix-x for their contribution to the discussions which led to the final report; many other people who helped in the organization of the conference, in particular Mrs. E. Bassam; and Mr. S.G. Simmons and The Palantype Organisation Limited for assistance in translation and in the production of this volume.

London P.A.
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Paper 1

National health survey systems in the European Economic Community–Final report

P. Armitage

1.1. Summary

This paper is based on the report of a Workshop Conference held in October 1975 to discuss the possibilities for collaborative action between countries of the European Economic Community (EEC) in the conduct of various forms of health survey. Health interview surveys offer the principal opportunity for such action, and it may be possible to incorporate health questions into multi-purpose international surveys. Health examination surveys are less likely to be developed widely in the immediate future. Hospital in-patient discharge records are collected routinely in many countries, and further international cooperation seems feasible. These possibilities are now being kept under continuous review by a working party.

1.2. General background

This paper is based on the proceedings of a conference held at the headquarters of the Commission of the European Communities, Brussels, from 6–8 October 1975. It was organized under the sponsorship of the Specialized Working Group on Epidemiological and Statistical Research and Clinical Trials (SWG EPID) of the Committee on Medical Research and Public Health (CRM), which falls under the Committee for the Coordination of Scientific and Technical Research (CREST). The 29 participants were drawn from the member countries, from the Commission, from countries outside the Community with experience in national health surveys and from the World Health Organization (WHO).

1.3. National health survey systems : the scope of the conference

The purpose of the conference was to study the possibilities for cooperative action between the countries of the Community, and perhaps other countries, in the field of 'national health survey systems'. This phrase implies systems of continuous or regular health surveys, on a national or at least a regional scale, covering a wide range of health conditions. The conference was therefore not primarily concerned with single surveys carried out at one point in time, or surveys which are very restricted geographically or relate to one narrow aspect of health. Nevertheless, such restricted surveys are often relevant in discussions of more general systems, and they were frequently referred to in the course of discussion. Similarly, the conference was not primarily concerned with systems for complete registration of vital events or of cases of specific disease; again, however, these topics cannot be completely excluded from consideration. Indeed, general survey systems must be viewed as part of the total system of health information, inter-relating in various ways with the other parts.

Three broad categories of national health survey can be distinguished, according to the source of the health information. In health interview surveys, information is obtained from members of the general population. In health examination surveys, clinical examinations and tests are performed by doctors, nurses or other qualified persons. Finally, there are surveys of records provided during the course of routine health care, for example in hospitals or in general practice. Each of these categories is discussed in detail below.

1.4. Health interview surveys

In a national health interview survey a sample of the general population is selected, usually by choosing a random sample of households and including every member of the chosen households. Trained interviewers are normally used, and the information may be provided partly by one member representing the household, and partly by interviewing each person separately. Questions may relate to the prevalence and incidence of illness and disability and the consequent restriction of activity; to the use of health services and associated social services; to the extent of self-medication; and to attitudes towards the health services. It is important also to collect demographic and other socio-economic information, to which the health data may be related.

The value of information provided by respondents about their own health is clearly limited by their imperfect technical understanding, by reticence and by failures of memory. Nevertheless this information complements that derivable from medical sources, and is often the only way of studying those facets of ill-health which are not referred to the health services. Another advantage of personal interviews is that information about an individual's health, about his contact with different health services, and about his socio-economic characteristics can be automatically linked: linkage of *routine* records is a particularly troublesome problem. A further point about household surveys is that they provide simultaneous information about all members of a family, which is often of socio-medical importance.

National health interview surveys have been conducted at intervals for perhaps the last half-century. Continuous systems date from the 1940s and 1950s. The Japanese National Health Survey, for example, has been running since 1953; the US National Health Interview Survey since 1957. In the UK the Survey of Sickness ran from 1943 to 1952, and has been followed (since 1971) by the health section of the General Household Survey.

A continuous survey system provides the staff with stable working conditions and enables high standards of data collection, editing and processing to be established. The ability to amalgamate data over time periods of moderate length means that reliable information is available for small sectors of the community which in any one survey would give rise to high sampling errors. A continuous system also provides a basis for occasional surveys on special topics, which can often be mounted with less cost and more speed than if they were organized independently. There will, of course, always be a place for *ad hoc* surveys which for administrative, scientific or other reasons cannot conveniently be fitted into a general system.

In some countries, continuous health surveys form part of a multi-purpose socio-economic survey system. This arrangement has the practical advantage of economy in cost, and the technical advantage that the socio-economic information which would be needed for the health data is automatically collected. Linkage with health information available from other sources (for example, mortality data) can often be carried out by special studies, perhaps on a sub-sample.

1.5. Health examination surveys

A small number of countries, notably the USA and Japan, have instituted continuous health examination surveys. These involve physical examinations, clinical and laboratory tests, and various other technical measurements. They can provide continuous monitoring of many of the physical, physiological, and perhaps psychological characteristics of a population. They can also yield medical data of greater technical content than can be obtained from interviews, including the discovery of cases not previously diagnosed, the estimation of prevalence of diagnosed diseases, and the establishment of population reference data for various measurements.

Health examination surveys require highly qualified personnel and moderately elaborate apparatus, and are considerably more expensive per individual studied than are interview surveys. This fact tends to reduce the sample sizes used and to increase the sampling errors of estimated characteristics of the population. The practical need to concentrate the technical apparatus geographically leads to a high degree of clustering in the sample design, which again increases sampling error.

A method commonly used in health examination surveys is for a basic core of information to be obtained routinely, and for certain branches of medicine to be explored more fully from time to time. In the US Health Examination Survey, successive 'cycles', each lasting several years, have dealt with different age groups or with broad topics such as nutrition and health.

Health examination surveys present many problems. These include the need for careful quality control programmes to guard against measurement error and to ensure standardized examinations; the safeguarding of confidentiality of information and the need for advance liaison with health service personnel in areas visited. All are soluble.

1.6. Records of health care

Information about national morbidity is, of course, available from the various branches of the health services. However, routine records, whether clinical or administrative, are often unreliable in quality. A carefully planned sample survey, in which special measures are taken to improve the quality of the data, may therefore be more valuable than an attempt to study a total population of records.

This category of survey is clearly very wide, particularly if it is taken to include administrative information about health care delivery as well as clinical data about patients. Two particular types of study deserve special mention : hospital in-patient discharge records, and general practitioner records.

In certain countries, information about hospital in-patients is collected on a national scale. This may be done by sampling of discharge records, or on a 100 per cent basis, in which case samples of the whole population of records may be used for special enquiries. Linkage with other health information about individual patients may be carried out, and methods have been developed to protect confidentiality.

Records of primary medical care must be an important part of a health information system. Unfortunately the routine records of general practitioners are often not sufficiently reliable to form the basis of a survey. Several examples exist of surveys using doctors who are chosen for their willingness to keep careful records rather than by random selection. The information may therefore not be representative of the whole of general practice. These surveys tend to last for only a year or two: continuing surveys, except on a pilot scale, seem rare.

1.7. The uses of health survey data in health planning

The various forms of survey described above provide different information about a nation's health and about the functioning of its health services. They can all be seen, therefore, as part of a general health information system which collectively is an essential foundation for the planning of health services. Health examinations, and medical records concerning primary and secondary care, provide a continuous picture of medically authenticated morbidity, indicating the relative needs of different sub-groups of the population for various forms of medical treatment. Health interviews extend this picture to include illness and disability not under current treatment, as well as utilization of, and attitudes towards, health services.

Health planning involves allocation of priorities between competing projects. In principle it might be possible to do this in a rational manner, so as to maximize the benefit in some sense. Discussions are taking place in Canada about the allocation of priorities between preventive medicine measures, using estimates of the effectiveness of such measures derived both from health interview and examination surveys and from special aetiological studies. The difficulties are daunting, not least that of putting mortality and different forms of morbidity on the same scale of measurement. More usually, health service planning will be based on informed judgements as to merits of alternative choices, and national health surveys can play an important part in providing the information on which these judgements are based.

There is increasing interest in many countries in the construction of health indicators analogous to the more widely used social indicators. These are indices, summarizing various measurements of health, which can be used for broad descriptive purposes (summarizing trends, making comparisons, and so on), and for the formulation of policy (for example, in the definition of targets). National health surveys of various types naturally play an important part in providing the information on which these indices are based.

1.8. The uses of health survey data in epidemiological research

Epidemiology is concerned with the distribution of disease throughout a community, and can usefully draw on national health survey data. The diagnostic deficiencies of health interview data will make this type of survey less useful for some epidemiological research than health examination surveys or medical record investigations. Sometimes, however, the epidemiologist may be more concerned with symptoms than with diagnosed disease, either because these are the explicit object of his study or because they are predictors of later disease. In such situations health interview surveys may be an entirely appropriate research tool. Interview responses about health service utilization, moreover, can be of great value in epidemiological studies of medical care.

1.9. Cost-benefit aspects of national health survey systems

National health survey systems yield many benefits : are they worth the cost? Any attempt to apply cost-benefit analysis in the health field raises formidable difficulties. Where the benefits are diffuse and open-ended, as are those of a health information system, the attempt is almost useless. Health information systems in general can be supported on the grounds that every advanced country allots high priority to health service expenditure, that a health information system is an essential feature of an effective health service, and that experience shows that good health information systems can be maintained without an unacceptable level of expenditure.

Within the health information system the various forms of national health survey system require separate justification. Health interview surveys can often be associated with continuous or periodic socio-economic surveys, at relatively little extra cost. The benefit in quality which is conferred by continuity of survey organization is particularly important in health interviews. Health examination surveys are more expensive per individual, and cannot so readily be integrated with other survey systems. The case for a continuous system is thus weaker than for interviews, although it should not be dismissed. Special surveys in specific branches of medicine will continue to be done, and the extra cost of a continuous system may be proportionately low. Health care record surveys can often be done at moderate cost, since the records are already available, although perhaps in too crude a form to be immediately usable. The case seems particularly strong for coordinating records of hospital in-patient care, through a continuous survey of discharge records.

Health survey results will be used, by health planners or others, only if these users are fully aware of the potentialities of the data. The budget for a health survey system must provide adequately for rapid analysis, interpretation and publication of results, otherwise the cost and effort put into the execution of the surveys will be largely wasted.

1.10. Health survey systems in the EEC

The extent of development of health survey systems is affected by many factors; among these are the nature of the health services, the general level of development of health information systems, the extent to which several administrative authorities share responsibility and the existence of a national social survey organization. All these factors vary widely within the Community, and the development of health surveys varies correspondingly.

Two countries, the Federal Republic of Germany and the UK, have regular or continuous health interview surveys. Questions on illness and accidents are asked in one of the quarterly supplementary samples in the Microcensus programmes in Germany; and there is a detailed continuing section on illness and use of medical services in the multi-purpose General Household Survey in the UK. France has had two decennial surveys, in 1960 and 1970. A university-based scheme operates in the Flemish-speaking areas of Belgium. In the Netherlands a continuous national system is planned to start in 1977.

There appear to be no continuous national health examination surveys in the Community. Complete or sample surveys of hospital in-patient records exist in Denmark, Germany, Ireland, Italy (every 3 years), the Netherlands and UK. Surveys of general practice records are carried out on a pilot or spasmodic basis in a few countries and are being discussed in others.

1.11. Health survey systems outside the Community

The US Health Interview Survey and Health Examination (now Health and Nutrition Examination) Survey have already been referred to. Japan is one of the few countries other than the USA to maintain health interview and examination surveys over a long period of time, although there are many examples of nation-wide surveys conducted once or repeated for a few years. The WHO has consistently encouraged the development of health surveys, particularly in relation to the needs of developing countries.

The health survey system currently being planned for Canada will be of great interest to countries in the EEC which are considering the establishment of similar systems within the near future. The Canadian surveys are expected to start in 1976.

1.12. Collaboration within the Community

There appears to be a keen interest in health survey development amongst representatives of national health administrations and research organizations. The prospects of collaboration in health interview surveys seem good. Several countries have now gained experience in, or are actively planning, such surveys and can share their experiences with other countries. Moreover, most countries conduct socio-economic surveys and the Commission already plays a part in ordinating and standardizing them. It would clearly be advantageous to incorporate health uestions in these multi-purpose surveys.

nternational cooperation of this type will not only help to spread expertise throughout the ommunity. It will also provide an important tool for international comparative studies of health. Routine health statistics tend to be highly dependent on the local health service structure. Health nterviews, by contrast, can be highly standardized in different countries and much of their substance is largely independent of the nature of the health delivery system.

The cost considerations referred to in section 1.4, the lack of experience of national health examination surveys in the Community, and the absence of any infrastructure to which they could be attached, suggest that no immediate plans should be laid for the development of continuing health examination surveys on a Community basis. The possibility of future developments should, however, be retained. In the meantime cooperation between the countries of the Community is likely to continue in more restricted types of health examination survey; a survey of deafness in children, for example, is under current consideration.

Hospital in-patient discharge record surveys exist in several countries, and there is active interest in others. This seems a fruitful area for collaboration, and SWG EPID has already appointed a small sub-committee to investigate the current situation more closely and to make proposals for cooperative action. The work of the sub-committee should continue to receive support from the Commission.

Surveys of primary care are difficult to organize on a continuing basis. It is virtually impossible to obtain random samples even within one country. International studies are further complicated by the differences in primary medical care facilities in different countries. It seems wise to postpone collaborative action here until more experience has been gained in individual countries.

Every survey provides more information than is immediately analysed and published. As health surveys become more extensively used it will be increasingly important to make primary data available to other workers, and so to minimize unnecessary duplication of effort. This applies both to surveys covering a wide range of health and to those on more restricted topics. The case should therefore be explored for setting up some form of archive in which health survey data could be deposited and made widely available.

Although no permanent central organization is called for, it is important that the current developments in health surveys in the Community be kept under continuous review, and that the scope for collaborative action be explored in more detail. Contact should be maintained and strengthened with countries outside the Community with experience in national health survey systems, and with relevant international organizations. These aims can best be achieved by a small working party, with perhaps one representative from each member country and a small number of representatives of the Commission. Terms of reference for such a working party were suggested in the recommendations from the Workshop Conference. This working party has now been set up under the Chairmanship of Dr. W.P.D. Logan.

1.13. Recommendations to the Specialized Working Group on Epidemiological and Statistical Research and Clinical Trials

The recommendations of the Workshop Conference have been approved by the medical research committee, CRM, and will form the guidelines for the working party referred to above.

1. The Workshop Conference on National Health Survey Systems in the European Community has discussed the national health interview surveys being carried out or planned in countries within the Community and elsewhere. The Conference recognises the importance of such surveys, which provide information about aspects of health not available through routine records, and about the utilization of health services. Such information is essential for the planning of health services and is of considerable epidemiological interest.

The Conference therefore recommends to the Specialized Working Group on Epidemiological and Statistical Research and Clinical Trials that an *ad hoc* working party should be formed, with membership drawn from the countries of the Community, with the following responsibilities, and recommends also that their activity should receive the support of the Commission.

(i) The examination of existing national health surveys and related health information systems in the countries of the EEC, and the dissemination of information about these systems throughout the Community.

(ii) Study of the need for, and the possibilities of, standardization and calibration of existing health survey procedures.

(iii) The development of a collaborative programme directed towards coordinated health survey activity in the countries of the EEC.

(iv) Liaison with other international and national organizations with related interests.

(v) Exploration of the possibility of introducing health interview questions as an integral part of the collaborative socio-economic surveys already organized by the Commission.

(vi) Consideration of the formation of an international archive system for survey data.

2. At the same time, the Conference recognizes the experience gained in various countries in national health examination surveys. It recommmends that the possibility of future collaborative health examination surveys should be kept in mind, particularly in view of the need to identify population groups at risk to various diseases.

3. The Conference recognizes the importance and feasibility of national systems for hospital in-patient discharge records and endorses the current activities of CRM in supporting international standardization and collaborative work in this field.

Paper 2

Epidemiology and health statistics in the European Economic Community

L.R. Karhausen

2.1. Summary

This paper discusses the work, developed from the provisions of the Treaties which instituted the European Coal and Steel Community (ECSC), the European Economic Community (EEC), and the Atomic Energy Community (EURATOM), of the Commission in the health field, and the limitations of this work. It gives details of some of the studies carried out in the fields of radiation protection, environmental protection, and the use of computers in medicine. It describes the mandate, defined by the Politique de la Recherche Scientifique (PREST) which was given to the new Medical Research Committee (CRM), in 1971, and the main areas on which, it was suggested, the Committee should focus its attention; the setting-up of the Scientific and Technical Research Committee in 1974; and the *ad hoc* and Specialized Working Groups which are sub-committees of the CRM. The paper also covers in detail the terms of reference of, and topics of interest to the Specialized Working Group on Epidemiological and Statistical Research and Clinical Trials.

2.2. Introduction

On April 19 1951, six European countries (Belgium, France, Italy, Luxembourg, Holland, and the Federal Republic of Germany) signed the Treaty of Paris which instituted the ECSC. It subsequently became the nucleus of the EEC which was established by the same countries in 1957, to develop a common European market, and the EURATOM which was established at the same time to pool the resources of the six nations for the development of peaceful uses of atomic energy.

The three Treaties stress their economic basis, although they also have technological and political aims. But many of the provisions call upon the Commission to take action in health fields, notably public health, industrial hygiene, and radiological protection, as well as in medical and biological research. These provisions are more binding on the member countries than is usual in international organizations. The EEC Treaty specifies that economic and social progress implies a continuing improvement of standards of living, and the human and natural environment. The ECSC Treaty mentions that technical progress should be accompanied by protection against occupational hazards. The EURATOM Treaty is also concerned with the protection of workers and the general population against radiation hazards.

Cooperation between member countries has also developed outside the framework of the Treaties, and here the Commission plays a role in promotion, coordination, control, and standardization. Many agreements, recommendations and declarations have resulted in the exchange of scientific information, and in some cases, in legal agreements between countries in the field of health regulations, particularly concerning the radiological protection of populations, and three areas of industrial hazards – coal mines, iron mines and steelworks.

2.3. Research related to radiological protection

The further development of nuclear energy in the EEC appears to be a prerequisite for the maintenance of the industrialization of its member countries. The production and utilization of nuclear energy carries a health risk for those people who are directly involved in these processes; and low level exposure of the general population to ionizing radiation needs to be considered seriously as a factor in the pathogenesis of neoplastic diseases that result in a decrease of the quantity as well as of the quality of life. It is evident that the dramatic changes that have occurred in the ecology of the countries of the Community through changes in the chemical, physical and atmospheric environment, as well as in the biosphere, add to the complexity of health problems that need to be studied in order to maintain and improve the health of the people in the Community.

The first objective of the 'Biology – Health Protection' multiannual programme is the study and evaluation of risks associated with ionizing radiation. Research proposed in this context concerns:

(i) the scientific and technical bases needed for the establishment of radiation protection standards, and adequate protection of workers and the general public;

(ii) the biological and ecological consequences of the use of nuclear energy and ionizing radiation, to ensure protection of the various components of the environment.

Certain diseases have been treated, and some still are, by radioisotopes. Groups of subjects who had received such treatment were selected for the purpose of epidemiological investigations. At Heidelberg the research project Thorotrast supported by the Bundesministerium für Forschung und Technologie and by EURATOM involves the long-term follow up of patients who were exposed to Thorotrast during the thirties and the forties. Thorotrast carriers and adequate controls were found in five hospitals in the Bundesrepublik, and 114 patients are at present under surveillance. Three years after the initiation of the project, the study group clearly differs from the control group: they have a higher incidence of severe liver disease with four primary tumours and ten cases of cirrhosis. In addition, there was one case of aplastic anaemia and one plasmacytoma. The study continues. The causes of death of 124 Thorotrast carriers was also traced; the breakdown is given in Table 2.1.

TABLE 2.1. *Analysis of cause of death for 124 Thorotrast carriers*

Cause of death	Number of carriers
Tumours of the liver	46
Cirrhosis of the liver	17
Leukaemia	5
Other malignant processes	17
Other causes	39

The analysis of the results suggests that 50 per cent of the deaths can be attributed to Thorotrast.

For an average Thorotrast burden of 25 ml. and a period of 30 years before malignancy appears, the mean α-ray dose to the liver is 750 rads. If one assumes an average Thorotrast burden of 15 ml. in those patients who die from leukaemia, and again 30 years to malignancy the total α-ray to the bone marrow can be calculated to be 170 rads. Using Spiess and Mays postulate of a linear relationship between bone sarcomas and average skeletal dose, this α-ray dose rate to the skeleton would suggest an expected incidence of 1.6 to 3.1 spontaneous bone cancers per 1000 Thorotrast patients. Preliminary data suggest an observed incidence of 2.4 to 4.6 cases of bone cancer per 1 000 Thorotrast carriers.

A similar study has been conducted in Munich at the Kinderpoliklinik. Patients who were injected with ^{224}Ra during the period 1946 –51, for the treatment of tuberculosis, ankylosing spondylitis and other diseases, were traced. The data currently available suggest an increased risk of malignant and benign bone tumours, and a probable increased risk of kidney and liver disease as well as of cataract, whether the patients were juvenile or adult when exposure occurred. The total incidence of bone sarcomas increased with dose in approximately linear fashion at 1.5 per cent per 100 rads average skeletal dose for juveniles and 0.9 per cent per 100 rads average skeletal dose for the adults.

In addition to the last project, a study on possible radiation effects on about 2000 patients suffering from ankylosing spondylitis who from 1948 to the present have been treated in several German university hospitals by ^{224}Ra injections began in 1971. The aim is again to calculate the average skeletal doses received by these patients and to correlate them with late effects.

Radioactive iodine is a very important isotope in the radiological protection of populations. It might also play a role as a factor of hyperthyroidism in view of its increasing consumption as a food additive and as iodized salt. Thyroid uptake in subjects free from thyroid diseases is conditioned by various nutritional factors. The most decisive of these factors is probably the quantity of iodine supplied in the diet, which means that the mean thyroid uptake in normal subjects is a reliable indicator of the dietary iodine supply in a particular community. The purpose of the project is to study geographical variations of thyroid uptake in normal European man. The method consisted of assembling, with the collaboration of 25 European centres of nuclear medicine, different series of data on the trapping of ^{131}I by the thyroid gland. The subjects included in the survey were chosen according to clinical and biological criteria which excluded any anomaly of thyroid function.

Preliminary results were obtained for almost 4000 subjects. They reveal the existence of marked regional variations in the average levels of thyroidal avidity for radio-iodine. Thyroid uptake at 24 hours varied between 25 to 40 per cent of the ingested dose for most of the towns studied in Italy and the south of France, whereas it ranged between 45 to 69 per cent in Germany. An intermediate level was observed in northern France and the Benelux countries. These figures are significantly higher than those obtained by similar methods in the USA where the iodine intake is much higher. An intercalibration study will be done between the laboratories which collaborated in this study.

Within the same field of development of radiological protection norms for human populations, a dietary survey was conducted in the six member countries. Radioactivity in the food chain is a public health problem which was very important some years ago because of radioactive fallout and it will be of increasing importance in the coming years with the fast development of nuclear energy. In order to be able to estimate the intakes of radionuclides in the different areas of the Community and by different age groups, a survey of food intake in the Community, which included at that time (1963 to 1965) the six original countries, was planned.

Nine thousand families were studied in eleven regions spread out over the six countries. Total family consumption was measured. Each family was studied for a week and all food consumed was weighed at home by the investigating team. A method based on linear programming was applied to the data in order to obtain estimates of food consumption by age groups. Monthly mean intakes were calculated in each of the eleven regions for nine age groups. An attempt was then made to validate the mathematical method used to derive the mean individual intake by age group from the rough family data. A small group of families were studied in Rome and both family consumption and individual consumption were measured. The validation study showed that the method provides a rough estimate of food consumption by age groups, but that it does not always give a very good fit.

The increased utilization of ionizing radiation for therapeutic applications has brought the problem of the precise knowledge of absorbed dose to a crux. It has been shown for instance that in the case of the treatment of malignant tumours by ionizing radiation, the passage from a condition of tumour reduction to an uncontrolled and often catastrophic situation can be caused by a variation of the absorbed dose of only a few per cent. The Commission has initiated a European Dosimetry Intercomparison Project (ENDIP) to allow comparison, inside the EEC, of results obtained at various neutron energies and in various irradiation situations by different groups.

2.4. Environmental studies

The Commission has been involved in the protection of the environment as well as in the protection of man from harmful effects of environmental change or pollution. There is a double rationale for these activities, scientific measurement and the assessment of norms and of acceptable levels of pollutants in the environment for legislative purposes.

An epidemiological survey is currently being conducted on the relationship between air pollution and respiratory disease in children. The purpose of the study is to determine the influence of various air pollutants on respiratory symptoms, respiratory disease and ventilatory function in school children.

Two air pollutants are commonly measured in the EEC : smoke or particulate matter, and sulphur dioxide. The choice of areas in which to investigate children has been determined by the prevailing levels of these pollutants. In each selected area, a random sample of schools will be drawn to yield about 1 500 children in the age range 7 to 10 years. The peak expiratory flow rate, height, and weight of the children will be measured by visiting teams of trained field workers, who will also interview the parents to obtain histories of symptoms and some demographic data. The data from each country will be transferred locally on to punch cards but will be processed centrally.

Projects are also being undertaken on the intercomparison and standardization of techniques. The importance of comparability of measurements to ascertain the significance of numerical values obtained in different laboratories is well-established and has resulted, as previously mentioned, in ENDIP. A similar intercomparison programme has been initiated by the Commission to compare and validate the numerical values obtained by different laboratories in determining. levels of mercury, cadmium, and lead in blood and in urine, as well as the activity of ALAD (delta-aminolevulinic acid dehydratase) in blood and ALA (delta-aminolevulinic acid) in urine.

These studies are most important for epidemiological studies of risk factors and for the establishment of acceptable levels of contaminants in the environment or biological fluids.

2.5. Use of computers in medicine

A research group on Biomedical Information set up a sub-group for the study of hospital discharge summaries. Standardization of the structure and terminology of medical records has been a subject of practical experimentation on several occasions in many countries.

The aim of the sub-group is to ensure that summaries:

(i) serve the needs for communication between physicians at the three levels of medical care;

(ii) make available data for research and for relevant epidemiological studies;

(iii) serve as a basis for medical audit and for evaluation of health care;

(iv) to serve the needs of hospital and health care administration.

The working party prepared a preliminary document which will be discussed further in collaboration with the Specialized Working Group on Epidemiological and Statistical Research and Clinical Trials of the CRM.

2.6. The Committee for Medical Research

Except in some limited fields, the Commission originally had no actual responsibility in matters of public health in general. Most of the projects which were conducted, had been set up for specific reasons, and although the Commission's activity in these fields was very important, epidemiology and health statistics for example were not tackled as such until recently. Except for specific questions, these topics remained the responsibility of the national governing bodies, national health authorities, or national or international scientific bodies.

Consequently the various activities of the Commission at the scientific level in medico-social research may sound like a set of isolated projects. They find their unity only within the general aims of the Commission's policy.

In July 1971, it was decided to fill in the gaps in the Commission's activities in the medical field. A working party was set up to discuss coordination in medical and public health research. The mandate was defined by the PREST working group who deemed it anomalous that 14 years after the Rome Treaty 'the European researchers in the biomedical field were pursuing their activity ignoring largely the work going on in other laboratories in the Community'. PREST acknowledged that there were 'official clubs' in various sectors of medical research which permit a certain exchange of information on ongoing projects and on their development. The main areas for common action were considered to be early diagnosis, prevention of and screening for diseases, and problems of rehabilitation. PREST concluded that the most promising sectors were those of epidemiology and of medical biology.

On June 15 1974, a new working party, the Scientific and Technical Research Committee (CREST) was set up in place of PREST, together with diverse sub-committees covering fields such as research, energy, medicine, and agriculture.

The Medical Research Committee has two main tasks:

(i) the coordination of national research policies in the field of medical research and of health care policies – this implies the examination and comparison of the national policies of member states, and the identification and comparison of the objectives of member states to determine their common goals and the appropriate means of achieving them;

(ii) the definition and proposal to CREST of research of interest to the Community, taking into account possibilities for participation in some of these projects by non-member countries, particularly European ones.

CRM set up two *ad hoc* groups: one on the problem of road traffic accidents, more precisely on 'Psychological and toxicological factors in road traffic accidents'; and a second group was set up on the problem of deafness, including the detrimental effects of noise, and taking account of congenital factors. In addition CRM set up three Specialized Working Groups: one on Epidemiological and Statistical Research and Clinical Trials; one on Biomedical Engineering; and one on Medical Biology; and it took over the previous Standing Committee on Monitoring of the Seriously Ill.

The Specialized Working Group on Epidemiological and Statistical Research and Clinical Trials (SWG EPID) met for the first time in 1974. The terms of reference of the Group specify that it will be responsible for promoting the exchange of information and the dissemination of knowledge, and on the other hand for the preparation of proposals for research projects. The Group may propose to the CRM such steps as are desirable to achieve these objectives, including organizing training courses, exchange of personnel and collaborative studies of methodology. The Group is also supposed to assist the CRM by carrying out particular studies at its request and by assisting the other Working Groups or *ad hoc* groups in their work.

Some of the other sub-groups also engage in epidemiological activities, such as epidemiological studies on deafness in children, the measurement of blood pressure in epidemiological studies, or studies of the risk factors of road traffic accidents.

It was decided that initially the SWG EPID should give preference to cooperative ventures – research projects planned at the level of the Community but financed on a national basis with a final pooling and analysis of the results. The activities of the Group have not yet reached that point although much preliminary work has been done.

A working party was organized at Århus on the question of training of general practitioners in the field of epidemiology. Two working parties have discussed the question of registers of congenital malformations and of twins, and a feasibility study will start soon simultaneously with a pilot study in a small island in Denmark (Odense).

Other problems are under consideration including: the medico-social aspects of ageing; the question of hospital statistics in the nine countries; drug monitoring; epidemiology of suicide in adolescents and young people; registration of employees exposed to carcinogenic compounds; and problems of comparability of diagnosis of schizophrenia and of rehabilitation of chronic psychotics. It is too early yet to know what actions if any will come out, but it is likely that some concrete propositions will be made within the next year to the CRM.

The present Workshop on National Health Survey Systems was one of the first proposals discussed in the Group. It is no exaggeration to say that the SWG EPID and the CRM consider this topic to be of the greatest importance.

Somebody wrote once in Punch that medical statistics are like a bikini, since what they reveal is interesting but what they conceal is vital. However, it might be more appropriate to conclude with MacMahon who wrote, of the US National Health Survey, that it offered the potential for prompting as great an advance in epidemiological knowledge as did the introduction of death registration in London four hundred years ago.

Paper 3

Health information–general aspects

M.R. Alderson

3.1. Summary

This paper gives the author's definition of an Health Information System (HIS), formulated on the basis of his experience in a Regional Health Authority in England; the objectives of such an HIS; and points which must be considered before a system is initiated. It discusses the data which must be included, and the staff and facilities necessary. It reviews the types of data which are required for the routine management and planning of health services; and the various problems found in using routine data for these purposes. The paper goes on to discuss the difficulties encountered when an attempt is made to convert a wide variety of data, such as are collected by different parts of the National Health Service in the UK, into a system which will provide information – both on the use of all aspects of health services in a patient's sickness episode(s), and more importantly on the outcome of this usage. It also suggests broad strata of information which should ideally be available; and considers ways in which the data routinely collected might be made to approach this ideal.

3.2. Introduction

An HIS is defined as a mechanism for the collection, processing, analysis and dissemination of information required for the organization and operation of health services, and also for research and training (Alderson 1973).

At its basic level, in terms of a national health system, an HIS is often associated with the collection and processing of data from a single and specific treatment unit or service facility. Other systems may be located at local, regional, or national levels of health care. There is a relationship between the location of the system and the uses to which the information it produces is put, with emphasis on management at local level and strategic planning at national level. There is also an important relationship between the uses and the necessary timeliness of the information; a faster speed of processing is required for information used in management.

This paper is a personal note on the present state of health information systems, with some comments on anticipated future developments. It is important to emphasize that the note is somewhat parochial, being based on experience in one region in England supplemented by comments from colleagues elsewhere in the UK. The note does not reflect Department of Health and Social Security policy for the development of information systems; at the present moment the Department are encouraging review of current systems and local initiative depending on requirements and the resources available for such work.

3.3. Objectives of an HIS

The primary objectives of such a system are to assist in the management of health services at all levels; the managers involved in operating the health services at local level require detailed local information; statistics produced at periodic intervals that show the general performance of the health services are necessary at several management levels; and planners need information to study the current functioning of services and trends in demand and work-load. Since a large proportion of the data coming into an HIS is from treatment units, it is essential that the system assists and interests clinicians by providing them with feed-back on their data that facilitates the study of clinical problems. Managers, planners, and clinicians will frequently require *ad hoc* data, and the HIS should serve as a framework for a range of research studies. To play an effective part in this range of activity requires the production and presentation of very different sets of outputs. Currently, there are no definitive models for comprehensive and successful systems, and research must in part be devoted to their development. At this time, the system should also serve as a teaching or learning instrument for those involved in the work.

3.4. Improving an information system

There are four aspects to be considered in making improvements to a health information system:

(i) the resources available for the system – resources of data, staff, expertise, and processing equipment;

(ii) the problems faced by all levels of management; this includes study of the problems facing those responsible for administering hospital and community health services, at national, regional, and local levels;

(iii) how information is currently used and whether decisions on current problems are reached without need for or use of information;

(iv) the extent to which more efficient handling of presently available data could assist a more profitable examination of problems faced by management, and the need to extend the collection of routine or *ad hoc* information.

Providing there is acceptance of the basic solution derived from these considerations, the necessary improvements to the system can gradually be introduced; if possible this stage should be monitored so that the outcome of the changes is observed. Unless this is carefully done it will be impossible to determine whether the revised provision of information has aided management and justified costs.

3.5. Resources

Data

The foundation for present information systems in the UK is the available routine and periodic data collected within the National Health Service. Historically, this has extended from the collection of mortality data, the notification of infectious and other specific diseases, data on hospital discharges, records of contact with other health agencies, and sickness absence records, to the periodic collection of data from health questions in ongoing sample population surveys. Also relevant is a range of information on: the workload carried by the health service; the cost of the health service, including costs for staff, expendables and capital plant; demographic and socio-economic particulars from the census and routine vital statistics; and environmental monitoring.

Staff

Staff must be included for the collection, preparation, processing, analysis and interpretation of the material. Some of these staff will be health service personnel, incidentally assisting in data collection, whilst others will be specifically working in the 'information' field. The background and training of staff associated with the development of computer systems and statistical analysis will be very different from that of staff running routine service applications. Development of sophisticated systems may be slowed through lack of skilled staff or the state of technology, whilst a routine system can founder from lack of key personnel, such as data preparation staff. The management lines in any health information organization require careful consideration to give the optimum balance of control between those responsible for the development and implementation of information systems and the health service users of the system.

Where there is an absence of routine data, requirements for staff to carry out *ad hoc* surveys must be considered.

Facilities

Once an information system extends beyond the mere clerical manipulation of data there is a spiralling requirement for access to data processing equipment. It is usual to find data handling being carried out on computers which are also used for payroll and other financial activities. This may lead to a non-optimal configuration, and data processing staff accustomed to relatively static financial systems who resist flexible software that may be consuming in machine time. In addition, there are frequently constraints upon the availability of machine time, with priority allocated to the financial work, especially payroll runs, and to medical activities such as patient scheduling (for immunization for example).

3.6. Information requirements for management

For some management functions, the information system should provide for the routine surveillance of the efficiency of the service. This should be by periodic presentation of tabular data on a variety of aspects.

Trends in demand for services

Simple indices of changes in demand for health services are in themselves useful, even if the complex issues underlying trends cannot be clarified. Ideally the system should present data on new attendances with general practitioners; new requests for the services of ancillary staff in the community (such as health visitor support or district nursing); investigations requested by general practitioners with direct access to hospital diagnostic facilities; new referrals to hospital out-patient departments; numbers of emergency/booked/planned/waiting-list admissions to hospital; and work load of service departments, such as pathology and X-ray, in the hospital.

Trends in bottle-necks

At periodic intervals material should be presented on the queues and waiting-lists for various services including: numbers of patients awaiting availability of resources in the community, such as patients requiring, but not receiving, routine visits from the district nurse or other supporting services; the numbers of patients waiting, and the mean waiting-time, for urgent and non-urgent appointments at out-patient departments; the waiting-lists for in-patient treatment, in the form of an estimate of bed-days required rather than simply numbers of patients, and preferably tabulated by individual consultant and diagnostic category; delay time for complex investigations such as cardiac catheterization, respiratory function tests, and so on; and the number of patients in acute beds in hospital awaiting transfer to long-stay care in chronic hospitals, admission to sheltered accommodation in the community, or discharge to their own, or a relative's home upon mobilization of community resources.

Use of resources

Ideally it would be advisable for an HIS to include a complete profile of the deployment of staff and physical facilities, not just an inventory of resources but in relation to services provided. For instance there should be information about the work of the general practitioner and the ancillary staff in the community; it should not be just a count of items of service performed, but should relate this workload to specific patient-care groups. Similarly one requires information which quantifies the use of out-patient facilities, in-patient facilities, and service units in hospital. The collection and presentation of this information on use of resources should be problem orientated; one could then look at, for example, the total contribution made by all aspects of the National Health Service in the care of the expectant mother, and not just the number of admissions to maternity homes, or attendances at clinics for expectant mothers.

The material on use of resources will be most usefully presented in three rather different ways; first within a district, it may be used to indicate the distribution of resources between treatment problems (for instance, to contrast the bed and staff allocations for the care of children and the care of the elderly, or the mentally ill). Secondly, clinicians caring for a particular category of patient could be given data comparing the use of resources in their own district with the other districts in the region (for instance one may look at variation in lengths of stay for particular conditions between consultants in one district and from district to district). Thirdly, at area and regional level there will be interest in looking at comparisons between districts, pooled data for the areas and the region as a whole, and any relevant information that is published or directly available from central government.

Outcome of care

The examination of use of resources becomes much more meaningful when variation in practice can be related to outcome of care. Those responsible for information systems will have to devise means of acquiring useful indicators of outcome of care; judicious manipulation of data may augment the currently available case-fatality rate with complication rates, recurrence rates, and re-admission rates. Some information can be obtained on a simple basis by collating re-admissions of individual patients to a hospital or group, using the unit number, although the accumulation of extended patient files raises a number of important issues. Much more difficult to obtain will be indices of recovery, re-ablement, and patient satisfaction; some of this material will have to be collected by special studies, and these cannot be replicated in every region for even the major patient care groups, let alone specific diagnoses. Information on trends in the outcome of care will be required, and these trends within a district must be compared with data for the other districts in the region (and with any relevant published material for the country).

Monitoring innovations in health care

Any new development in medical care (whether a gradual evolution in methods of delivery of health care, or more major change due to innovation and the introduction of new programmes of care) must be monitored to assess the impact of the change. For instance with a preventive scheme, such as immunization, it is essential that statistics are presented on the uptake of these procedures, identifying the sub-groups of the population who do not participate in the programmes, and contrasting the subsequent morbidity and mortality in the protected and non-protected. With the introduction of administrative or medical changes in the care of patients, such as the intensive use of out-patient therapy, day-surgery, day-hospitals and decreasing lengths of stay in hospital, it is important to monitor, among other things, time on the waiting-list, number of operations performed, bed occupancy, length of stay, turnover interval for in-patients, and outcome of care.

3.7. Information requirements for planning

The term planning is used by different people to mean very different things, but it can be defined, in relation to health services, as the process culminating in decisions regarding the future provision of the correct balance of domiciliary, out-patient, and in-patient facilities for the investigation, treatment, and care of all 'perceived health needs' of the community. The planning process involves a long time-scale and is particularly concerned with planning for the health needs of the next generation. Excluded from this definition is the examination of current resources and current demands resulting in the short-term reallocation of these resources in order to meet these demands more effectively 'tomorrow'. This latter process is part of the function of management and has been covered in the previous section.

The simplest way to plan is to identify the current workload, quantify the resources used to meet this workload, and relate this to the population in the catchment area; in this way 'norms' for the provision of care can be derived. These norms can then be applied to the projected population figures in order to obtain anticipated requirements. But such an approach is likely to perpetuate current mismanagement. To produce a more precise approach one requires detailed information about the diseases currently affecting the population, and on to this one needs to build estimates of: trends in the incidence of disease; possible changes in the attitudes of the population to health and health care; future variations in delivery of care; impending changes in therapy; and the effect that any new therapy is likely to have on the prognosis of disease. In addition, planners will make use of all the management information on the current situation.

The use of routine data to provide answers to this type of question is obviously limited; much of the necessary information will have to come from research, both with the medical field and from other disciplines. It is here, also, that the techniques of operational research come into play; providing one knows the current demand and the way in which this is being met, one can build a model of the health care system, simulate change in the system, and observe in the model the repercussions that, for example, alteration in the deployment of resources has upon workload and throughput.

3.8. Requirements of other users

If the above needs of management and planning are to be fulfilled it is evident that a sophisticated information system will be required. Though the interests of clinicians and other research workers will be different again, the information system should be invaluable as a source of background information and a framework for specific studies. If a clear picture of the present functioning of the health service and quantification of the problems it faces can be obtained the material should also be of great use in teaching programmes.

3.9. Problems of routine data

It is important to comment briefly upon the problems, before discussing in further detail the uses to which routine data may be put. The first problem is completeness of the data; for example, with the UK Hospital Activity Analysis (HAA)† it is important to see that a form is actually completed, coded and sent through to the computer system for every patient who is discharged from hospital. Yates (personal communication 1974) provides an example of a completion figure of 97 per cent (comparing a sample of forms received with discharges from administrative records of patients discharged) providing a false sense of security. When the returns for general surgery were examined in detail, there were no deaths in the sample, and it transpired that the records of patients who died were held until after the next, infrequent, meeting concerned with deaths in hospital. In this way the usual records system, including the HAA clerical procedure, was avoided. This emphasises that incomplete recording may create a serious bias, as well as an under-estimate, of workload.

Perhaps more has been written about the problem of accuracy of routine data than about any other aspect; before investing effort in the analysis and interpretation of material, it is important

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† A system for collecting and processing limited particulars for each person discharged from hospital (excluding maternity and psychiatric patients).

to make some check upon its accuracy. This should be done at periodic intervals, to identify the error rates for each item being entered into the routine system – this includes administrative, demographic and diagnostic information. By identifying the error rate it is possible to determine which items can be readily interpreted, which items require special effort to improve their accuracy, and which items are of such dubious value that they do not warrant collection. A study of the accuracy of Scottish hospital morbidity data has been reported by Lockwood (1971), who found a very low level of error in the demographic, administrative and diagnostic data. But these results differ from those of a special analysis of address codes by Gruer (1970), who found a considerable misallocation of addresses in certain rural parishes in Scotland, owing to the current system of postal addresses in rural areas. Wilson (1970) has indicated how logical errors can be detected by computer edit programs, giving, as an example, dates (entry to waiting list, admission, operation, discharge) which are the data most frequently found to be in error and the easiest to remedy. More complex is an examination of the extraordinary associations between diagnoses, or diagnoses and procedures, or modes of admission, and maximum time on the waiting list for particular diagnoses. Lockwood suggested that there was 94 per cent accuracy in the transcribing and coding of the principal diagnosis, which gives a discrepancy rate lower than that found by Alderson and Meade (1967) for comparable material, and by Alderson (1972) for the diagnoses recorded in cancer registration. Other reports from different fields are of the accuracy of addresses held by health centre records (Hannay 1972) and the general accuracy of general practitioners' records (Munro and Ratoff 1973). Kay (1968) compared social class coding carried out by practitioners, and by a trained clerk; he showed how the discrepancy rate in coding can be reduced to a considerable extent by using a centrally based and trained clerical coder. However, the drive for accuracy of routine systems has to find an optimum level, and not reach the point of diminishing returns. As Greenwood (1948) suggested 'The scientific purist, who will wait for medical statistics until they are nosologically exact, is no wiser than Horace's rustic waiting for the river to flow away'.

A rather different problem associated with routine data is created by delay in collecting and processing the material; this often occurs because the capture, coding, and processing are relatively low on the list of priorities of workers in hospital and computing centres, who are busy with other day-to-day pressures.

Problems frequently arise in the retrieval of data for certain special studies, and one aspect of this is the coding system used. In particular, the coding for the diagnostic and operative particulars may be of insufficient specificity for the particular needs of clinicians, and there is a need to adjust the codes so as to extend the range of diagnoses uniquely identified in respect of special data collected for clinical use. When analyses are extended over a number of years, a problem is created by the decennial revision of the International Classification of Diseases (ICD); a drastic revision creates considerable work for data processors, creates a problem for clerical staff who have to absorb the changes, and may in certain circumstances make comparison over a number of years extremely difficult or impossible.

A more general issue is whether the items handled by the system are appropriate to the particular problem for which the material is being analysed. As an example, different consultants vary in handling a complex clinical problem, and some discharge patients for a short spell between initial investigation and definitive treatment. Because these will be recorded as two separate admissions, the data recorded will not be appropriate to analyse length of stay by diagnosis. Other data deficiencies present themselves in examining of length of stay; it is not possible to tabulate by severity of the basic condition, or by availability of facilities for early discharge from hospital and for community care.

Having identified a particular use and a gap in the current system, the routines for data collection and processing may be so inflexible that it is difficult to add the highly relevant additional particulars to the system; the routine system rumbles on, incapable of presenting appropriate analyses. The main difficulty in devising a flexible system is that flexibility adds to the programing and data processing tasks, and may gradually move the local systems further and further away from a standard national framework. If flexibility is encouraged, to meet local demand, steps must be taken at the same time to see that comparability throughout the country is not lost.

In any discussion on information systems the issue of confidentiality is likely to be raised. The subject is clouded by misunderstanding and some ill-founded doubts; it is, however, an aspect that requires careful attention. Unless the profession and public can be reassured that no leak or misuse of stored information will occur, and that the benefits obtained from an HIS are required for the correct functioning of the service, there is a likelihood of continued obstruction.

The problems discussed so far are difficult enough; the final one is, however, the most difficult of all to deal with – how to make an analysis from the system acceptable to the potential user. This is not merely a problem of making the output presentable, and readily digested; there is often a psychological block on the part of the recipient to the acceptance of management data, particularly where this presents indications of variation in the use of resources. Forsyth and Sheikh (1971), in a review of the functioning of the 'cogwheel' system in England and Wales, have referred to the problems of the acceptance and use of management data.

3.10. The dilemma of extending a system

The above sections indicate the potential range of items that may be called for; the wealth of data is not required in order to bury statisticians in statistics, but stems from management information requirements. Before responding to suggestions that additional data be collected every item presently incorporated must be reviewed to see if there is redundant material. The next step is to consider which of the following courses of action is appropriate:

(i) addition of items to the list for routine collection on a 100 per cent basis;

(ii) collection of relevant data on a sampling basis, where the sampling frame may be fixed (10 per cent of all 'pathology' reports, for example), or variable (collection of 100 per cent haematology one year, and 100 per cent clinical chemistry next year);

(iii) collection of relevant data in a purpose-designed one-off survey;

(iv) handling of available data (and perhaps opinions of experienced staff, particularly on unmet health needs and anticipated changes in health care) in a simulation or other dynamic model;

(v) combination of two of the above approaches.

Implicit in the above is the need to plan any change in relation to clear cut requirements of potential users. It is essential that repeat collection of identical items does not occur for different purposes and that the total HIS is viewed as an interlocking set of subsidiary systems. Many *ad hoc* surveys will benefit from being mounted as a temporary extension of the routine data collection system, perhps using the latter as a sampling frame.

In addition to the problems of routine data mentioned in section 3.9, there are a number of advantages and disadvantages to the five courses of action. These are partly related to the specific category of management need, but are more closely related to the stage of development and mode of operation of the country's health service.

Because the problems faced by a health service are continually changing, the information system must be flexible and responsive. In many cases, the specification of the data to be collected and the mechanics of the systems to handle these is not clear cut. Judgement, and trial and error are required; and thus it is imperative that any innovations in information handling are carefully evaluated. This in itself is no easy task, but must be attempted in order to judge past actions and indicate the way ahead.

3.11. Towards an ideal information system

The previous sections have given some indications of the topics which an HIS should cover. In the past there has been a tendency for separate sets of data on workload, deployment of staff, and so on, to be examined in isolation. As the data base of the HIS gradually extends, it becomes practicable to relate the information on workload to use of resources; for example, there is available in the UK information on length of stay in hospital, which provides an indication of consumption of hotel costs and other basic costs per day's stay in a staffed bed.

Information on operations performed gives one an indication of use of theatres; the actual procedures carried out can be classified into major, intermediate, and minor to give an indication of throughput of the theatre. This can be converted into an index of 'surgery per theatre session'. If the data base can be extended to incorporate request and reporting systems for laboratory investigations, X-ray, ECG and other procedures one can link unit costs for this work to the cost of treating individual patients. Gradual extension of the information system in this way enables one to look at use of resources and costs in relation to the characteristics of the patient treated (specialty, consultant, diagnosis, age and sex, perhaps community support . . .). But unless there is some indication of the severity of the condition (and in considerable depth compared with mere diagnosis) one cannot relate the medical data to patient dependency and associated staffing requirements. Even more important are indices of outcome; case-fatality rate is of limited value and more detailed information on re-admission rate, complication rate, recurrence rate, and patient satisfaction must be sought.

This brings us to a major problem in the health information system as it stands in the UK at present. To provide these relatively simple outcome measures would involve data from all branches of the health service and beyond. Routine data of the types mentioned above exist only for the hospital service, and it is essential that the information system should be extended into care in the community.

In an ideal situation, one really requires to know – from routine data and many other sources:

(i) how many people in the community are suffering from incipient or overt disease?

(ii) what proportion of people contact their general practitioner?

(iii) for those who do contact their general practitioner, how does he deal with their particular problem; does he rely on his clinical judgement or request diagnostic investigations, does he prescribe treatment, does he continue to see the patient at intervals, or does he refer the patient to the hospital services?

(iv) for what proportion of patients referred to a hospital out-patient department is a clinical diagnosis made at their first attendance; what proportion have diagnostic investigations, reattend – and how many times – or are put on the waiting list for admission?

(v) for those patients admitted to hospital, what investigations, care regimes, or operative procedures are carried out, and what is their total length of stay?

(vi) for all these alternative forms of care, what is the outcome – in terms of both 'hard' data on mortality, recurrence, or complications, and 'soft' data on return to work and quality of life?

(vii) and how has the treatment affected the patient and his family, and how satisfied are they?

Only when such an extensive range of information becomes available is it possible to make valid comments on use of resources, costs, variation in medical practice within a given specialty, or the existing inequality of allocation of resources between different patient groups and different geographical areas.

These problems cannot be solved by the collection of desiccated statistics about the current state of affairs. Even when they are quantified, their solution requires value judgements. It is suggested, however, that by providing more precise information statisticians can help the health professions, administrators, and the public, to consider a series of alternative strategies, and to decide together how the service should be run in the future.

This may seem 'pie in the sky' but the concept has been around for a long time. Florence Nightingale (1863) advocated the regular collection of a wide range of standard particulars to ascertain the results of particular treatments and operations. She also suggested that the whole question of hospital economics, as influenced by diets, medicines, and comforts could be brought into examination and discussion; she was also keen to extend the collection of data to out-patients.

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Paper 4

National health survey systems in Belgium and Luxembourg

A.Z. Meheus

4.1. Summary

This paper points out that there are currently no national health survey systems in either Belgium or Luxembourg. It describes various specialized and *ad hoc* surveys which have been undertaken, and the systems for medical records which exist, especially those arising from health insurance schemes. It discusses the needs for, and feasibility of, further surveys; and describes new developments in the analysis of health insurance records, and the national registration scheme begun in Belgium.

4.2. Introduction

Health survey systems, on a national or regional scale, do not exist at present in either Belgium or Luxembourg; and the government authorities have no plans to introduce them in the near future. But there are several areas of the health infrastructure where health surveys, preferably on a collaborative basis, could be introduced.

4.3. Health interview surveys

The US Health Interview Survey, and the recently developed General Household Survey in the UK, provide some systematic data on acute and chronic morbidity and on the utilization of health services, in relation to the socio-demographic characteristics of the population concerned. This type of survey would be feasible in Belgium and could be developed by the National Institute for Statistics (Ministry of Economic Affairs), or by a National Institute for Health Statistics to be created as part of the Ministry of Health.

The National Institute for Statistics does conduct a decennial family budget survey based on a questionnaire put to a random sample of Belgian households. The main objective of the survey is to define the structure of the family budget for different population groups – blue-collar, white-collar, and non-active. But information is collected on the amount of money spent on five aspects of health services: pharmaceutical products; rehabilitation apparatus; services of medical and paramedical workers; hospital care; and supplementary health insurance. It must be stressed, however, that only those expenses not covered by the health insurance system (the so-called 'ticket moderateur') are studied; and the initial response rate in the 1973 survey was only 22 per cent of the sample, with a further drop-out of 25 per cent before the end of the survey, so that the information is very limited.

A research team from the Universities of Leuven, Ghent, and Antwerp, and the Flemish Society of General Practitioners, plans a series of health interview surveys in the Flemish-speaking part of Belgium during the period 1975–77. These are covered in more detail in Paper 18, but the general objectives are:

(i) to study latent morbidity by means of an interview survey of a sample of Flemish households; the study will not be restricted to physical factors but will include psychological and sociological determinants;

(ii) to analyse morbidity as seen by the general practitioner, by means of a registration system to be undertaken by a representative sample of Flemish general practitioners;

(iii) to assess public opinion and public education in health matters, by means of a more detailed interview survey;

(iv) to assess the relationship between public opinion and differential health care utilization;

(v) to analyse use of resources (except hospitalization) in relation to sociological and psychological characteristics of the population.

It is to be hoped that the experience gained in this research project, which is mainly based on the technique of the health interview survey, will lead to a national, continuous system.

In Luxembourg, a census of handicapped persons is carried out, using a questionnaire sent to all organizations concerned. Medical and sociological data on the handicapped person are collected with the main aim of evaluating the health needs of that population group.

4.4 Health examination surveys

In Belgium, some studies of prevalence, restricted mainly to morbidity of the cardiovascular and respiratory systems, have been carried out by university research teams, on both occupational groups, and non-selected populations in small geographic areas.

Medical examination surveys covering a broad morbidity range could be organized in specific age or sex groups by the Oeuvre National pour l'Enfance, which carries out prenatal and postnatal screening, and examinations on the under-fives, through school and occupational health services.

In Luxembourg, although no health examination surveys as such exist, there is a compulsory prenuptial examination, which collects data on blood group, and the results of some serological tests (for syphilis, rubella, and toxoplasmosis), and chest X-ray.

4.5. Medical records

Some hospitals in Belgium, especially university hospitals, have computerized medical records for some departments, and a patient discharge print-out listing administrative items, together with diagnosis is available. These could be used as a sampling base for surveys, although none have been undertaken as yet.

In Luxembourg, medical records are not yet standardized, but in two general hospitals (covering one-third of annual admissions to general hospitals) a questionnaire is systematically completed, which covers administrative and socio-cultural data on the patient, diagnostic information, and outcome of treatment. This is used as a discharge record for the hospital, and a copy is sent to the Statistical Department of the Ministry of Health. In two maternity units a continuous survey is organized which yields information on pregnancy, birth, and the newborn. For each birth a questionnaire, which is also the basis of the permanent medical record, is completed by the obstetrician and the paediatrician. This survey covers 50 per cent of all births in the country – 2 000 per year.

4.6. Health insurance records

Utilization of the health services in Belgium nearly always results in the production of a certificate for social security purposes. These certificates are collected by the insurance funds which partially or totally reimburse the patient for the costs incurred. The certificates can provide data uniquely coded by services provided – consultation according to type of physician, hospitalization, all diagnostic procedures, therapeutic interventions, and so on. As the whole of curative medicine in Belgium is organized on a reimbursement basis, these certificates contain very valuable information on the use of health services; their value in producing morbidity data is much more limited.

The whole population is covered by the health insurance scheme for what are termed 'major risks', hospitalization or major therapeutic intervention for instance, by a system of compulsory membership. This is extended, also on a compulsory basis, to cover 'all risks' for employed persons, pensioners, and their dependents; many independent workers have also joined voluntarily.

Information from these records could be gathered at two levels: within the insurance funds or in the Ministry of Social Security. At the national level, in the Ministry of Social Security, a computer-assisted analysis of these medical records is planned, at first on a sample basis. The major objective of this survey will be financial, that is to obtain information on the amount of money spent by type of health care received. The programs analyse:

(i) expenditure by the code number of the medical service, which will give indications of the usage rates for different types of service – consultations at general practitioners' offices, home visits, consultations with other physicians, radiography, laboratory tests, surgical interventions, and so on – covering almost the entire population;

(ii) expenditure by type of physician, which can also give valuable information on the costs of medical services provided by all kinds of medical specialists;

(iii) expenditure by individual person insured, which will provide analyses of the use of different health services by age, socio-economic group, geographical area, and so on.

Whether this survey is undertaken will depend on political considerations. Some health insurance funds have already organized surveys using samples drawn from their records, but the interpretation of the results is difficult because of certain selection factors.

In Luxembourg, the health insurance funds are supervised by the Ministry of Labour and Social Security. An annual report gives statistics on the utilization of medical services, and some statistics on morbidity relating to incapacity to work.

4.7. National registration

In Belgium, registration of all individuals has been undertaken to build up a national register; by January 1974, 8 200 000 inhabitants out of a total of 9 700 000 were registered. Each individual is given one national number which is used for identification on all records. This simplifies considerably administrative procedure, and facilitates future medico-social research, and sample surveys of all types.

Paper 5

Present activities in health information systems in Denmark

K. Dreyer

5.1. Summary

This paper points out that, although there are currently no national health survey systems in Denmark, there are well-developed registration systems for a wide range of diseases. In addition there are several systems in use for hospital in-patient registration, and it gives a detailed description of one of them – M70. The paper also covers the registration of psychiatric in-patients, carried out through the Institute for Psychiatric Demography; it describes the differences in the information collected from the two systems, and how the information can be linked. It details the uses of and outputs from the systems, and goes on to discuss the expected future expansion of registration to the field of hospital out-patient treatment and possibly primary medical care.

5.2. Introduction

The present situation in Denmark is that no continuous health survey is being carried out on a national or regional basis or covering a wide range of diseases. Efforts during the last 10 to 15 years have been concentrated on the establishment of national registration systems for specific diseases such as tuberculosis, cancer, heart disease and mental illness, from which information on the disease pattern in the population may be derived.

The Danish National Health Service, together with representatives of the medical profession and hospital administrators at local and regional levels, have implemented a number of registration systems for in-patients in Danish hospitals. The coverage as of 1 April 1975 was 92.6 per cent of all hospital beds, including beds for mental illness. Decisions have also been taken as to the scope of and output from a future registration system for cases seen in hospital out-patient departments.

Finally, the first steps have been taken towards an attempt to survey non-hospital cases, that is, cases seen by a general practitioner or a specialist practising outside hospital.

5.3. Registration systems for in-patients

The main purposes of these systems are:

- (i) to facilitate clinical and epidemiological research by improving access to information contained in the hospital records;
- (ii) to improve hospital statistics by a more detailed registration of services rendered, and thus to provide a better foundation for medical and administrative decisions;
- (iii) to make possible an analysis of the cost of in-patient treatment, by linking information on services rendered to information on hospital costs in terms of personnel, equipment, and so on;

(iv) to facilitate hospital planning at all levels – local, regional, and national – by improving the basis for the forecasting of future need for hospital facilities under different assumptions of population changes, methods of medical care, or progress in medicine.

The differences between the systems which exist are, however, mainly confined to technical details; the content of the registration, as well as the definitions and the classifications used, are the same in all systems. The data collected by the system for psychiatric in-patients differs slightly but even here the basic information is identical with that of the other systems. The following is, therefore, an account of one of the systems for somatic hospitals, the so-called M70 system, with some comments on the differences between this system and that for mental hospitals.

5.4. The M70 in-patient registration system

In 1968 the Danish National Health Service appointed a small working group to consider the establishment of a system for the individual registration of in-patients, based on discharge sheets. The requirements included:

(i) that the system should be simple enough to be used by all Danish hospitals, irrespective of size, and yet should allow for the inclusion of more detailed information, as a basis for scientific research for groups of patients with given characteristics;

(ii) it should also be a means of elucidating the relationships between hospitals within a region, and in the country as a whole;

(iii) it should be flexible enough to allow for future changes without unreasonable costs;

(iv) it should form the basis for uniform nation-wide hospital statistics and for the hospitals' own annual reports, and thus be a tool for future hospital planning on all levels;

(v) it should be operational as of 1 April 1970.

The resulting system is built up from a basic registration, common for all in-patients, which can be supplemented by permanent or temporary special registrations as needs arise. Furthermore, these special registrations may comprise all patients or special groups of patients, and their objective may be of a medical or an administrative nature.

Basic registration

Since all Danish hospitals were to use the system, it was necessary to avoid anything involving sophisticated methods for the local input. Information on identification, admission, discharge, and diagnoses and treatment is abstracted from the medical records at discharge by means of a specially designed sheet (Fig. 5.1). The information is transferred onto conventional 80-column punch cards. Identification, admission, and discharge data are contained in the punch card numbered '000', cards '001-020' are designated to diagnoses and treatment, one card for each registered diagnosis. The system allows for a maximum of one thousand cards for each admission, so that there are a total of 979 cards available for special registrations.

Identification. The identification comprises a code for the hospital and clinic, the patient's personal 10-digit number which includes indicators of age and sex, and the date of admission. This identification, which takes up 24 columns, is repeated on all punch cards, and establishes a link, not only between the different punch cards within the basic registration, but also between the latter and any special registrations. It is thus possible to utilize all information from the basic registration in special registrations.

Admission. The information about admission comprises the patient's marital status and residence, date of referral to hospital, hour of admission, place from which admitted, mode of admission, and particulars about all cases of accidents and suicide. Age and sex are not explicitly registered as they are given by the personal number.

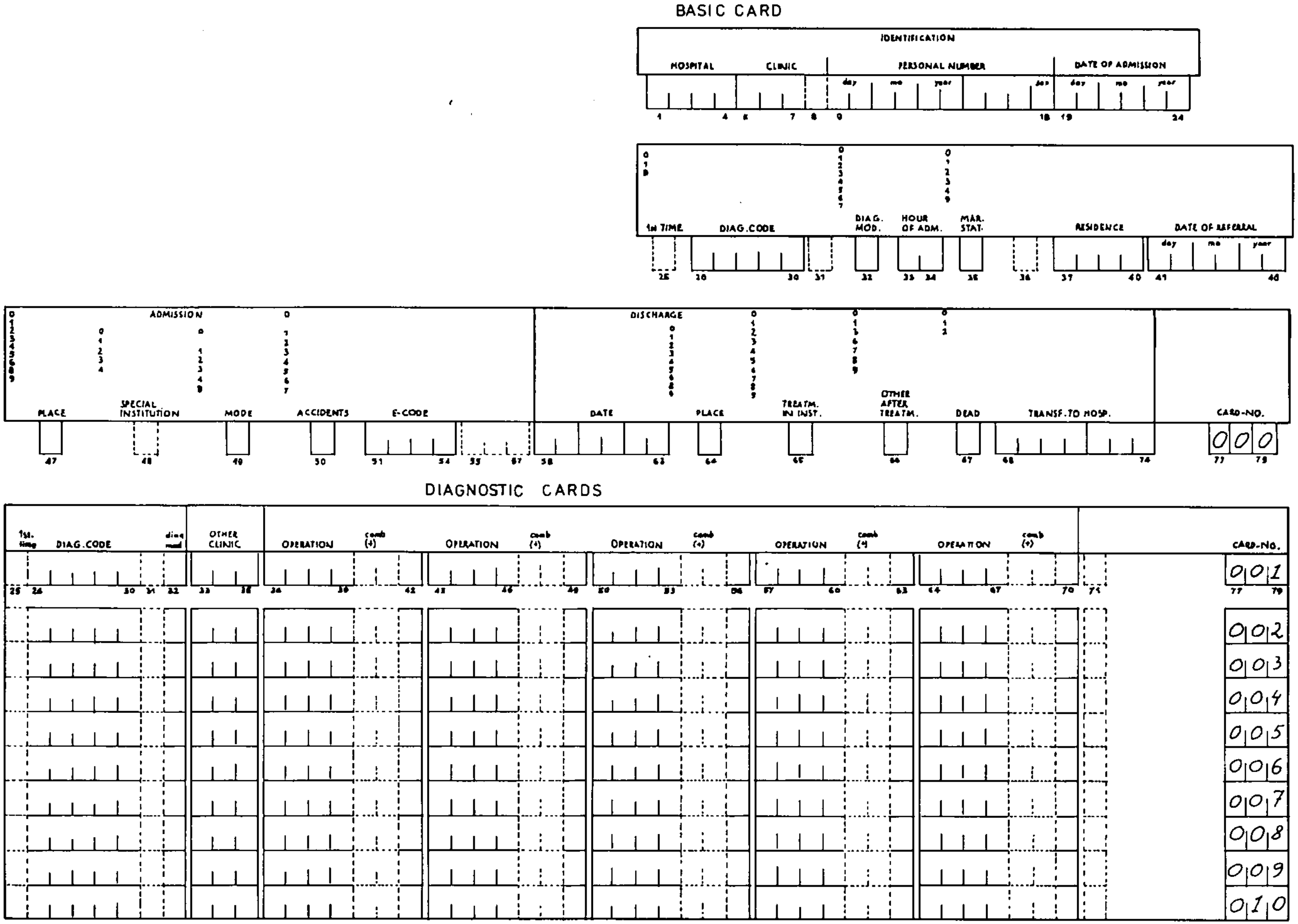

FIG. 5.1 *Registration sheets used to collect information on every patient discharged from all hospitals. Personal and administrative data are recorded on the basic card (card 000 for each patient); data for each registered diagnosis are recorded on cards 001-020.*

Discharge. The information about discharge follows the same lines: recording date, place, after-treatment (as out-patient or otherwise); deaths and transfers to other hospitals or clinics are also recorded.

Diagnoses and treatment. Punch cards 001 to 020 are used for the registration of diagnoses and treatment given for each diagnosis. The main diagnosis, also recorded in the basic card, is registered in card 001, and other diagnoses, if any, in card 002, 003, ...

The main diagnosis, in coded form, is also included in card 000 for the purpose of constructing tables where only one diagnosis appears, and to enable this diagnosis to be related to the personal characteristics of the patient without using the other parts of the record.

Coding

The first 24 columns of each card contain the identification, followed by a code to indicate whether or not this condition has been diagnosed previously by a hospital in the patient in question. The diagnostic code proper is based on an adaptation of the 8th revision of the ICD which has been expanded to 5-digits. An additional 6th-digit may be added if need arises, a possibility which has been utilized by various specialized departments. The final column allotted to diagnostic coding is used for modification of the diagnoses, such as sequelae, antea, or recidivans.

The remaining columns of each diagnostic card are used for treatment, usually surgical operations, but more extensive examinations and certain non-surgical forms of treatment such as complicated X-ray examination, reposition, biopsy, and cystoscopy have been included in the classification. The system used is an adaptation of a Swedish 4-digit classification, which allows for the addition of two more digits, one for further refinement of the code, and one for complications.

Each punch card can contain coding for up to five operations, with space between to indicate whether two or more operations are part of a complex surgical procedure. If more than five operations should be performed for the same diagnosis, the next card is used, repeating the diagnostic code. The three columns 33-35 are used to indicate that an operation has been performed by a clinic other than that to which the patient is admitted; in such a case the 3-digit code for the clinic in question is shown.

5.5. The registration system for psychiatric in-patients

The registration system for in-patients in mental hospitals and psychiatric clinics in general hospitals is centred on the Institute for Psychiatric Demography in Århus. The Institute has at its disposal a register of all admissions to Danish mental hospitals back to the 1930s (Dupont, Videbech, and Weeke 1974). This register was combined in 1969 with a computerized registration system for admissions to and discharges from State Mental Hospitals, and in 1970 all other psychiatric institutions were included in the system.

The input to the system comes from admission and discharge sheets, combined with discharge letters, or diagnostic information for patients staying longer than three months. As soon as an admission is notified to the Institute, copies of all information on the patient in question, from admissions to other psychiatric institutions, are sent back to the institution now treating the patient.

The information registered in this system differs slightly from that of the somatic system. There is no information on hour of admission, date of referral, and accidents, but on the other hand very detailed information on previous admissions to psychiatric institutions, and also on admission directly from, and discharges directly to such institutions are included. The basic information – age, sex, length of stay in hospital, residence, and diagnoses – is, however, included in both types of systems.

5.6. Output from the systems

Although the data collected vary, it is possible to combine information from all the somatic and the psychiatric systems in analyses of, for instance, diagnoses for hospitalized patients by age, sex, residence and length of stay, and also, by means of the individual person number, to link information from various systems on the same individual, to establish sequences of hospitalized illness.

All the registration systems in Denmark provide their users with diagnostic files, prepared cumulatively for each trimester. The somatic systems similarly print out surgical files, containing information on all operations performed. All systems prepare a number of annual tables, partly for use by the doctors, and partly for administrative use. All tables necessary for the annual reports to the National Health Service are also provided by the systems.

5.7. Future developments

It is expected that within a couple of years all Danish hospitals will introduce one of the systems now in existence. It is also hoped that a system for the registration of out-patient treatment in hospitals will be developed.

The next step to be taken – and a far more difficult one – is to set up information systems to cover illness not attended in hospitals. This will mean collecting information from general practitioners on illness treated in the primary health sector. At present the practitioners report to the Health Insurance System on services rendered, but no information on diagnoses is required. The system set up to handle the data is entirely concerned with the problem of transferring the right amount of money to the individual practitioner.

Discussions have just begun in the National Health Service on the best way to get the information required to fill the gap in our knowledge of the disease pattern in the Danish population, and a number of experiments will probably be carried out in the near future.

5.8. Appendix: Detailed codes for basic card

Column 25:	0	condition previously diagnosed in a hospital
	1	condition not previously diagnosed in a hospital
	9	not known
Column 32:	0	no modification
	1	case of observation, diagnosis not proved
	2	case of observation, diagnosis disproved
	3	late effects
	4	earlier
	5	recurrent
	6	treated
	7	operated
Column 35:	0	unmarried
	1	married
	2	separated
	3	divorced
	4	widow(er)
	9	not known
Column 36:	Size of household (no detailed code yet)	
Column 47:	0	own home
	1	other clinic (in same hospital)

	2	other hospital
	3	nursing home
	4	old-age home
	5	casualty ward
	6	other
	8	born in hospital
	9	not known
Column 48:	0	military establishment
	1	prison
	2	institution for mentally retarded
	3	other institution for handicapped
	4	institution for children and adolescents
Column 49:	0	acute
	1	through out-patient clinic for preliminary examination
	2	through other out-patient clinic
	3	other patients called in (from waiting list)
	4	called in according to decision on previous discharge
	8	born in hospital
Column 50:	0	not accident or (attempted) suicide
	1	traffic accident
	2	occupational accident
	3	accidents occurred during sports or athletics
	4	home-accident
	5	other accident (including (attempted) homicide)
	6	(attempted) suicide
	7	not known whether accident or (attempted) suicide
Column 55–57:	Waiting time in days before discharged (after treatment has been finished)	
Column 64:	0-4, 6, 9, see column 47	
	5	convalescent home
	8	died in hospital
Column 65:	0	in same clinic
	1	in other clinic in same hospital
	2	in other hospital
	3	in nursing home
	4	in old-age home
	5	in convalescent home
	6	in other institutions
	7	none
	8	died in hospital
	9	not known
Column 66:	0	out-patient clinic, attached to this clinic
	1	other out-patient clinic
	3	own physician
	6	other kind of out-patient treatment
	7	none
	8	died in hospital
	9	not known

Column 67:	0	discharged alive
	1	dead, autopsy performed
	2	dead, autopsy not performed

5.9. References

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Paper 6

Assessing the morbidity of the population on the basis of household surveys: the French household survey of 1970

Andrée and Arié Mizrahi

6.1. Summary

This paper considers the conceptual and observational problems inherent in attempting to estimate morbidity in the total population by means of a health interview survey of a sample population, on the basis of such a survey carried out in France in 1970. It describes in detail the methods used, considering aspects such as ensuring the representativeness of the sample, maintaining central control during the survey and standardizing the interviewees' replies, initial response rates and drop-out rates. It discusses the picture of the state of health presented by the survey in terms of disabilities, ill-health, and diseases reported, the use made of medical services and pharmaceuticals, and the reasons given for these uses, and some of the implications of these results; and it describes an attempt to synthesise an indicator of the degree of morbidity in individuals using all the information gathered. It mentions other sources of information on morbidity in France, and concludes with a discussion of some of the weaknesses of general population health interview surveys, and their importance.

6.2. Introduction

Assessing the morbidity of a population presents difficult conceptual problems. It is necessary to define the distinctions between normal and pathological states in general (Canguilhem 1966; Pequignot 1961) and to identify specific diseases. How can one decide, for instance, whether two symptoms or syndromes are caused by the same disease, represent two stages in a disease, or whether they indicate two different diseases? It is also necessary to consider the degree of severity of various pathological states. How can one compare poor vision with reduced mobility, or one day of confinement to bed with one day of interrupted activity?

There are also many problems posed at the observational level. Three aspects must be considered:

(i) nosological – the incidence and prevalence of various diseases and illnesses;

(ii) functional – the disability, or risk of disability, on a given day;

(iii) socio-economic – family, social, or professional repercussions of an illness.

Observations on all three aspects are necessary so that the relationships and implications of each can be considered. And again questions of definition and common measurement are raised. Account must also be taken of who is to provide the information. A doctor will doubtless give more specific nosological information, describing 'an infarction' rather than just 'heart disease', for example, but will provide no better functional data, and cannot provide the socio-economic data (Danish National Morbidity Survey 1960; Magdelaine, Pequignot, Rösch, and Ross 1963). The decisions made on these questions at the planning stage will determine the methods of observation and measurement.

This paper discusses the extent to which surveys carried out on a large, representative sample of households can improve knowledge of the state of health of a population, mainly by reference to the health survey of 7 400 households carried out in 1970 by the Institut National de la Statistique et des Etudes Economiques (INSEE) and the Centre Recherches et de Documentation sur la Consommation (CREDOC). The first survey of this type in France was undertaken in 1960; since then, although the knowledge of the use of medical services and pharmaceuticals has remained very important, the knowledge of morbidity has been developed considerably by a methodological survey in 1965/66, and the 1970 survey (Guillot, Mizrahi, and Mizrahi 1968; Guillot, Mizrahi, Mizrahi, and Rösch 1971).

6.3. The French health survey of 1970

The survey was undertaken by INSEE and CREDOC with the assistance of the Caisse Nationale d'Assurance Maladie des Travailleurs Salaries. The quality of the data was monitored by using liaison questionnaires which circulated between the interviewer, the INSEE regional administration and the medical staff of CREDOC throughout each phase of the survey. The data collected from each household was checked for self-consistency throughout both the collection and analysis programmes by the medical statisticians of CREDOC.

The information collected covered:

- illnesses and infirmities suffered by the population;
- medical services and products used;
- reasons for using the services and products;
- disability suffered, in terms of days confined to bed and interruption of activity;
- the demographic, social, and economic factors likely to affect these variables.

The study population comprised the 16 310 000 ordinary households – excluding hospitals, religious communities, boarding houses, and other institutions – of metropolitan France. A representative sample of 7 392 households (1:2206) participated; the method of selection allowed an equal chance for each household to be included in the sample.

Two survey techniques were used, direct questioning by the interviewer backed up by record books kept by the interviewee. The survey was carried out in different geographical areas during four 12-week phases, beginning on 15 January, 15 April, 15 July, and 15 October 1970.

The data collection processes of the survey

Detailed descriptions have been given by Mizrahi and Mizrahi (1970) and Gros (1972). Each household received five visits from the interviewer; one initial visit; three information gathering visits; and a final visit. The visits were made at three-week intervals, and each household's usage of pharmaceuticals and medical services was thus observed over a period of 12 weeks.

During the initial visit, the interviewer carried out a census on the individual members of the household, recording their main socio-demographic characteristics (age, sex, occupation, social benefits received, and so on), as well as details of any hospitalization in the previous year. Two types of information were collected to give measures of morbidity; details of medical or pharmaceutical treatment received during the previous eight days; and replies to a series of closed questions on chronic disease and disability.

The interviewer left a notebook with each household and asked members to record details of any medical products or services used between visits, and also expressly requested that the packaging of any medicaments obtained should be kept.

During the following four visits the interviewer completed a data form with the aid of the notebook and for each entry asked questions relating to the precise nature of the treatment, the payment made and the medical reasons. There was no bias of questions towards any particular type of disease or treatment.

During the final visit data were collected on additional topics such as weight and height, spectacles, hearing aids, and dental plates worn, nutritional habits, and impairment of mobility.

Attitude to the survey

Details of the participation rate are given in Table 6.1. The overall rate of participation is high (88.1 per cent) in view of the considerable effort required from each household. Information was collected throughout the holiday period resulting in a high percentage of subjects being away for long periods during the Phase 3 (13.7 per cent instead of 4.8 per cent for all the other phases).

TABLE 6.1. *Participation of households by phase*

				Details of households				
	Total in sample	Absent for duration	Available to participate	Refused to participate	Percentage refusals	Lost during survey	Completing whole survey	Percentage full participation
Phase 1 (15 Jan.–15 April)	2238	87	2151	153	7.1	85	1913	88.9
Phase 2 (15 April–15 July)	2268	124	2144	178	8.3	89	1877	87.5
Phase 3 (15 July–15 Oct.)	2270	310	1960	155	7.9	89	1716	87.6
Phase 4 (15 Oct.–15 Jan.)	2245	111	2134	148	6.9	100	1886	88.4
Total	9021	632	8389	634	7.6	363	7392	88.1

It can also be seen that refusal rates varied greatly according to region, from 14.3 per cent in the Paris region to 2.7 per cent in Alsace. 363 households dropped out of the survey before it was completed. Briefly speaking, in 16 per cent of cases this was due to medical reasons, in 34.8 per cent to having temporarily or permanently moved and in 4.4 per cent to hours of work or difficulty in expressing themselves in French.

Effective and theoretical duration

The theoretical duration of the survey period was 12 weeks, 84 days, for each household; the average effective duration of the observation period was 83.7 days.

Structure of the sample

Which households participated in the survey? Theoretically, if the sampling basis and selection had been perfect the 9 021 households within the scope of the survey should have provided a faithful representation of the 16 310 000 households in France in 1970. The sampling base comprised the total number of dwellings included in the 1968 census to which were added dwellings constructed subsequently; however, accurate statistics for the latter were very difficult to establish, and this introduced a degree of inaccuracy. Since not all of them were prepared to cooperate with the interviewers, the extent to which the households participating in the survey were representative of the whole is drawn into question.

Generally speaking, the sample group and the total population were very similar in structure: the 7 392 sample households appear to give a valid representation of the total population using socio-occupational category of householder, number of persons in household, sex, and age, as criteria for comparison. The sample group contained slightly more children and slightly less young men (between 20 and 29 years). It should be emphasized that the proportion of aged people was practically the same for both the sample group and the total population. On the other hand, it is obvious that the provinces are over-represented by comparison with the Paris region where the refusal rate was very high, as is usually the case in this type of survey.

6.4. The state of health of the population according to the 1970 survey

Using the survey data, the state of health of the population can be measured in three different ways:

(i) disability on a given day as disclosed by subjects, due to the particular illness from which each person was suffering. This is the measurement of the accumulation of various handicaps;

(ii) morbidity – counting the number of persons suffering from various illnesses or symptoms designated by a nosological code;

(iii) degree of morbidity – medical synthesis to measure the risks run by the sick person as a result of the illness from which he is suffering on the last day of the survey.

To carry out these assessments, it was possible to use either the answers to direct questions on illnesses and disabilities asked at the beginning and end of the survey, or the reasons given for using medical products and services, for being confined to bed or for any interruption of activities.

Disabilities and ill-health recorded by the sample population

Disability was recorded as difficulty in moving about; being confined to bed at home; being unable to work or study; and days spent in a hospital.

Difficulty in moving about was a listed statistic recorded on the first day of the survey on the basis of the interviewees' statements and related to persons of more than 2-years of age, not hospitalized on this day – 22 132 persons. It did not include disability due to transitory illnesses or periods of crisis but related to the general state of health of the person. The results are given in Table 6.2. It should be emphasized that these apparently small percentages imply that in 1970 about 320 000 of the non-institutional population were unable to leave their house for health reasons and that almost 850 000 required some type of aid to do so.

TABLE 6.2. *Percentages of the sample population suffering differing degrees of permanent disability at the time of their initial interview*

Degree of disability	Percentage of sample population
Confined to bed	0·19
Confined to house	0·49
Able to leave house with help from another person	0·55
Able to leave house with walking aid	1·21
Mobility somewhat impaired	6·96
No restriction of mobility	90·34

Being confined to bed was strictly defined in terms of entire days spent in bed and was recorded from observations made during the interviewer's five visits over the 12 weeks of the survey. Observations were recorded for both acute and chronic illnesses. Each person spends an estimated 1.63 days confined to bed at home per year, 1.03 for men and 2.19 for women. These figures can be supplemented by considering hospitalized persons as bed-ridden. On the basis of the survey the number of days per person spent in hospital is estimated at 2.31 per year, giving a total of 3.94 days confined to bed per person per year.

Interruptions in educational or occupational activities were also recorded during the survey. The duration of these interuptions was recorded in terms of current French law, that is including any holidays, so that an interruption from Thursday to Tuesday of the following week (inclusive) counts as six days. This rule was applied to annual holidays, with the exception of interruptions of educational activities which were only recorded during term time. For the pupil and student population, it is estimated that the average number of days absence per person per year for health reasons is 4.74, and for the working population 11.09 per person per year. These interruptions could in both cases be the result of either acute or chronic illnesses of considerable duration.

This information has been or will be analysed in relation to sex, age, the main socio-economic factors recorded during the survey – socio-occupational category of householder, level of education, number of persons in household – per unit of medical 'consumption', and type of insurance.

Diseases recorded by the sample population

Illnesses or infirmities were noted during the survey, either on the basis of affirmative answers to a list of questions on 23 groups of chronic diseases, including an open question for 'other diseases', or from the reasons given for being confined to bed, for any interruption of normal activity or for medical products and services being used, including those not prescribed such as pharmaceutical products to be found in the family medicine cabinet (Dejours 1974; Necker 1974). These various reasons were recorded by the interviewers exactly as stated by the subject and they are included in all questionnaires. When the terms used are not verbatim, the medical statisticians may have decided to regroup two reasons under a single heading from a consideration of the file as a whole or as a result of additional questions asked during the survey. Generally, the requirements to justify regrouping were fairly strict. The resulting analysis of morbidity is shown in Table 6.3.

This procedure ensures a degree of homogeneity in the information but by no means presumes to be a solution to the extremely complex problem of individualizing an illness or pathological process which can only be superficially described by the information provided by a household survey.

On the other hand, it seems important to point out that the duration of the survey itself does contribute some additional information on this matter. On the first day of the survey an average number of 1.12 chronic illnesses per person (answers to closed questions) and 0.22 existing acute illnesses for which products or services had been used during the preceding 8 days were recorded. This represents, on average, 1.34 illnesses per person on a given day recorded on the basis of a single interview. On the last day of the survey after observation of each household for 12 consecutive weeks and 4 more visits, the average number of illnesses per person was 1.72, an increase of more than 30 per cent.

The use of a household survey to determine the state of health of the population is therefore greatly dependent on the surveying technique selected.

Reasons for using medical services or products recorded over 3 months

Since this concerns reasons given by the members of the population and not illnesses, the framework selected makes provision for administrative reasons (to obtain a certificate, health check-up), vague symptoms (stomach ache, heart diseases) as well as more precise diagnoses. However, the allocations to medical classifications have been tested to ensure that they correspond with the ICD. For each product or service, provision was made for the indication of up to three different reasons for usage; and when medical consultations are considered, 7.5 per cent took place for two different reasons and 1.9 per cent for three reasons. In the majority of cases this concerned old people with complex pathologies.

An analysis of the reasons for using medical services and products is a kind of analysis of clientele which depends greatly on the classification considered. Table 6.3 shows the percentage of instances when 24 groups of diseases were offered as reasons for visiting the doctor (Lecomte 1974*a*), for the purchase of pharmaceutical products (with or without prescription) (Lecomte 1974*b*), and for hospitalization (during the previous year). A breakdown of total illnesses and

TABLE 6.3. *Diseases reported by the sample population analysed by 25 categories of morbidity*

	During the 12 weeks of observation			% of admissions to hospital during previous year
	% of cases reported	% of medical consultations reported	% of reported purchases of pharmaceuticals	
Infectious diseases	1.05	2.37	2.68	2.50
Influenza	1.71	2.91	2.89	0.61
Endocrine, metabolic and blood disorders	1.42	2.70	3.54	1.72
Cardio-vascular disorders	6.21	11.14	16.44	4.33
Varicose veins and ulcers	2.80	1.61	2.11	1.00
Tumours	0.60	2.85	1.68	5.94
Respiratory ailments	2.76	4.80	5.25	2.67
Allergies	1.09	2.25	1.82	0.83
Diseases of the nervous system	0.60	1.47	2.33	1.17
Mental problems	6.25	4.65	7.08	4.06
Ailments of the digestive system	13.25	10.37	12.81	17.28
Urinary diseases	1.68	1.74	1.64	1.61
Genital and obstetric problems	1.77	4.61	2.90	23.50
Skin diseases	3.89	3.73	3.69	1.94
Diseases of the skeleto-muscular system	8.70	9.35	8.59	3.0
Acute ENT problems	8.61	9.21	9.19	1.89
Chronic ENT problems	1.90	1.22	0.70	3.33
Sight problems	11.32	2.60	0.54	0.67
Other ophthalmic ailments	1.36	1.21	0.76	1.56
Accidents and traumas	2.34	6.40	2.15	13.17
Diseases of the mouth and teeth	13.14	(0.74)	1.56	0.67
Congenital malformations and diseases of early childhood	0.75	0.78	0.44	2.78
General symptoms not associated with one system	3.95	4.50	7.09	3.50
Preventive measures or administrative problems	2.69	5.28	1.24	0.22
Totals on which percentages are based	49 982 cases	21 490 medical consultations	873 388.26 F.	1 799 admissions

reasons recorded throughout the three months of the survey is given for reference. This analysis enables the disease groupings to be considered according to the frequency with which they occur among the population and to the type of treatment which they entail. Thus, visual defects appeared very frequently and are chronic, but they require very little treatment; accidents and traumas are infrequent, acute, but require considerable treatment (hospitalization); whereas diseases of the skeleto-muscular system are very frequent but above all require community care. Obviously more detailed classifications would be of greater interest; however, this is outside the scope of the present paper.

From this type of result:

(i) existing known illnesses of the population can be distinguished, according to the type and degree of treatment required in a standardized way for the whole population;

(ii) the reasons for the use of medical products and services stated by the population can be compared with those given by the medical services, in particular the hospital morbidity statistics (public hospitals) published by the Ministry of Health, and with surveys of doctors with private practices.

Degree of morbidity

Finally, morbidity can be described from a prognostic point of view. An experiment was attempted on the basis of surveys carried out in France in 1960 (Magdelaine, Mizrahi, Mizrahi, and Rösch 1967) and in 1965–66 (Mizrahi, Mizrahi, and Rösch 1973). On the basis of all the questionnaires and available information on each household, a medical statistician attempted to determine the degree of morbidity for each individual, at the time of their final interview, in the form of an indicator with two components – risk of disability and risk of mortality.

This indicator is synthesised, integrating medical knowledge and statements made during the survey. It makes possible the comparison of sub-populations both, for instance, from the point of view of perceived morbidity and the use they make of medical services and products for this perceived morbidity.

6.5. Other sources of data on morbidity in France

Numerous statistics on morbidity of the population are routinely prepared. The majority of these statistics could be obtained on the basis of data collected during household surveys.

Survey of 'suppliers' of medical care

There are two basic requirements for a given instance of treatment, a 'consumer' (patient) and a medical care 'supplier' (member of the medical profession). Information regarding this instance of treatment, the medical reason on which it is based, the various characteristics of the patient (age, sex, occupation) or the 'supplier' (specialist field) could be obtained from the former (household survey) or from the latter (survey of medical care 'suppliers').

Hospital morbidity statistics. Since 1969, figures have been obtained on a regular basis from public hospitals. For each hospitalization in the public sector a statistics sheet is drawn up giving the age and sex of the patient, the reasons for hospitalization and the outcome. This survey, carried out by the Ministère de la Santé (1974*a*), is published each year. Although a valuable contribution, this survey does have two weaknesses. Firstly, there is a high level of non-response and secondly, it does not extend to hospitalizations in the private sector (which represent one admission in two). Methodological studies are just under way to improve the survey in these two respects.

Survey of doctors in private practice. Two surveys of this type are currently in progress in France. The first, which has been in operation for several years, is being carried out by a private company, IDREM-DOREMA, for the pharmaceutical industry and is primarily concerned with medical prescriptions, morbidity being of secondary importance. Approximately 1 600 doctors are involved. Each doctor fills out a sheet indicating some of the characteristics of the patient (age, sex, occupation), the illness(es) observed and the pharmaceutical prescription for all consultations over a period of one week. Some of these data have already been used and published by the Ministère de la Santé (1974*b*) under the terms of an agreement with IDREM-DOREMA.

The second survey was carried out by INSERM and involved 1 800 doctors, each interviewed for one day. This took place in 1975 and the results are not yet available.

Examination of sickness benefit files

The majority of instances of medical treatment result in the payment of sickness benefit. In view of the confidential nature of medical information, the data currently forming the basis of surveys on a national scale are accounting documents. A fairly comprehensive description of the use of medical care is produced.

Causes of death

This type of data has been collected and used in France for many years, as in all countries in which statistical methods have been developed, and is published regularly.

6.6. Conclusion

There are a number of gaps in the information gathered from random representative samples of the population. Our first reservation concerns the link which seems to exist between the phenomenon studied, morbidity, and the acceptance of the survey: the existence of a serious illness in the household seems to be a cause of refusal to participate in, or dropping-out of the survey. Although refusal and drop-out rates are relatively low, this link may lead to a systematic underestimation of pathology of the most seriously ill persons.

Secondly, the institutionalized part of the population is not taken into account. Although this concerns only a small number of persons, their omission could cause a systematic biasing of results due to the greater morbidity of hospital in-patients and those living in caring institutions. The household survey should be systematically complemented by a survey of institutions.

Thirdly, the subjects are not very familiar with certain diagnoses, either because they have never been asked about them before or because they have never been informed of them. All sources of information include an element of error or inaccuracy. However, data supplied by households are not as bad as is commonly believed that is they are closer to those supplied by doctors than would be expected. Sick persons are very interested in their health and generally know fairly precisely from what illnesses they are suffering (when the sick person gives information which is not very precise, often the doctor is unable to supply better information).

Lastly, certain illnesses are regularly not disclosed or badly described by interview subjects, especially alcoholism and mental illnesses in France in 1970. This is definitely the cause of the most serious bias in the overall description provided by the general table of morbidity. This bias can only be reduced by the absolute respect of statistical secrecy and by an attempt to explain the survey to the interview subjects.

Despite these reservations, surveys of considerable random samples of the population seem the only way to obtain information on the morbidity of the population as a whole, including those persons who never or hardly ever need treatment from the health service. The data obtained can be compared with that from other sources: administrative statistics or surveys of medical 'suppliers'. Furthermore, households seem to be unique in that they can provide information of certain kinds such as days confined to bed, difficulties of greater or lesser importance, self-medication, and so on. In a developed health statistics system, household morbidity surveys, like 'supplier' surveys, occupy an essential place between administrative statistics and statistics on the cause of death.

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Paper 7

Health statistics in the Federal Republic of Germany: present activities

I. Huschenbeth

7.1. Summary

This paper discusses the value of mortality statistics, case-related morbidity statistics, and person-related morbidity statistics; and the provision of these by surveys of the general population, of general practitioners' patients, or of hospital patients. It describes the population health survey programme in the Federal Republic since 1963, covering aspects such as reporting period, breadth of survey, and coding; and goes on to discuss some of the problems of such surveys.

7.2. Introduction

The state of health of a population is usually measured by means of mortality and morbidity statistics. Mortality statistics are limited in value because they take into account only a single cause of death, and in future some means of indicating the multiple disease pattern in a patient at time of death will have to be considered. German health statistics have been biased towards mortality, but the importance of morbidity statistics is recognized. Morbidity can be induced by disease or accident, or it can be present from birth onwards; it can be acute or chronic; and can lead to disability or death.

7.3. Morbidity statistics

Prevalence and incidence are measured by 'case' and 'patient' statistics. Case statistics cover episodes of disease, accident, and disability, so that one person could be counted several times. The patient statistics, however, cover the whole spectrum of injuries or disabilities affecting one person.

Case-related morbidity statistics

The case morbidity statistics serve only a limited purpose. They usually include only certain types of diseases, the statistics of notifiable diseases, for example, or cover only particular groups within the population, as with statistics from statutory health insurance. The various case morbidity statistics available in the Federal Republic of Germany are detailed in Table 7.1. These are statistics currently published by the administration and official statistics from ministries or other insurance bodies.

In addition, there are some incomplete statistics on recognizable congenital and stillbirth malformations, collected on the basis of reports from physicians and midwives assisting at delivery. However, there are difficulties regarding the liability of reporting such malformations and these statistics are still at a preliminary stage.

Patient-related morbidity statistics

The patient morbidity statistics, on the other hand, provide important information of the state of health of the population, particularly as details of the demographic and social-economic background of the patient can be linked to the medical data. It would be possible to produce these statistics from surveys:

(i) of the general population;
(ii) of consultations with general practitioners;
(iii) in hospitals;

only the first method is currently being used nationwide for the whole population.

General practitioner surveys. Surveys at general practitioners' surgeries, or medical examinations, are very time consuming and involve a lot of work. Experience in this field is limited and statistics are only available through work on protection of the juvenile workers of some Bundesländer, and (on minor disabilities) from the first medical examination of military recruits.

Hospital surveys. Surveys in hospitals include only selected cases and injuries from accidents. The resulting reduction in the coverage of the statistics is, however, somewhat counterbalanced by the simplicity of the method and the relative reliability of diagnosis. For some time the Federal Republic of Germany has been trying to develop statistics of hospital diagnoses. Experience in this field has been obtained since 1969 in Schleswig-Holstein, where at present 42 per cent of all acute disease hospitals (52 per cent of beds) are participating in a diagnostic statistics scheme. Within a few years all acute disease hospitals in Schleswig-Holstein will be included. The data cover hospital discharges or deaths, classified by medical department or specialist clinic; up to three diagnostic categories based on the ICD; duration of illness; sex; age; payer of hospital charges; and treatment given. The Bundesgesundheitsrat attaches great importance to the provision of statistics on hospital diagnoses, and believes that a survey covering all hospitals is desirable. This was declared by statute on 11 February 1971, and preparations for such a survey are in hand. The statistics will cover age, sex, marital condition, nature of admission and discharge, length of stay in hospital, and it will be possible to register up to five diagnoses for each patient, using the ICD as recommended by the WHO.

Other surveys. On a more specialized and localized scale, there are cancer registries, notably in Hamburg and the Saarland. Incidence, prevalence, and detailed morbidity statistics are available using the definitions recommended by the Council of Europe.

7.4. Population health surveys

Population health surveys have the obvious advantage of showing the state of health of the population in the widest sense. In contrast to the other methods, data are collected on ill-health for which no help has been sought from the medical services.

In the Federal Republic, population health surveys began in 1963, with an experimental trial, and have taken place in 1966, 1970, 1972, 1973, and 1974. In the past they have been carried out separately from, but using the same sample population as the Microcensus follow-up surveys, which has meant that the necessary demographic and socio-economic data have also been available. The Microcensus surveys are carried out in every household within random study areas, which are selected using the regions delineated for the full population/occupation census as a sampling frame. Foreigners living in the study areas are included, but military personnel are not. From 1976 onwards, the health surveys will be carried out as part of the Microcensus programme every two years (sampling fraction: 1 per cent and 0.25 per cent). The necessary statute has been issued for questions to be included on:

(i) the most important risk factors and health indicators for the population, such as detrimental environmental factors, and smoking habits;

(ii) use of health services, for example, the frequency and purpose of medical

Statistisches Bundesamt 1. Huschenbeth

Übersicht über die Morbiditätsstatistiken in der Bundesrepublik Deutschland, Stand: Juli 1975

Wiesbaden, 16. Juli 1975

Gegenstand der Nachweisung	Fallbezogene Morbiditätsstatistiken 1											Personenbezogene Morbiditätsstatistiken						
	Meldepflichtige Krankheiten													Krankheiten u. Unfälle				
	Tuberkulose	Sonst. nach dem Bundesseuchengesetz meldepfl. Krankh.	Geschlechtskrankheiten	Gesamtst. d. Rehabilitation 2)	Reha.-Maßnahmen 2) (in Vorbereitung)	Behinderte (in Vorbereitung)	Straßenverkehrsunfälle	Gesetzl. Unfallversicherung	Gesetzl. Rentenversicherung	Krankheitsarten in der gesetzl. Krankenvers.	Priv. Krankenversicherung	Körperbehinderte 1966	Kranke und unfallverl. Personen 1966	1970	1972	1973	1974	Körperl., geistige u. seel. Behind. von Kindern 1974
1. <u>Grundlagen der Erhebung</u>																		
1.1 Rechtsgrundlage	(Bundesseuchengesetz 18. 7. 1961)		Gesetz z. Änderung d. Gesetzes z. Bekämpf. v. Geschlechtskrankheiten, 25. 8. 1969	Geschäftsstatistik	Schwerbehindertengesetz, 29.4.1974		Ges. z. Durchführung einer Straßenverkehrsunfallstatistik, 18. 5. 1961	Geschäftsstatistik				2., 3., 4. Verordnung über Zusatzprogramme zum Mikrozensus						
1.2 Periodizität (Berichtszeitraum)	v., j.	m., v., j.	v., j.	j.	j.	5 J.	m., j.	hj./j.	j.	j.	j.	April 1966 (4 Wochen)	April 1966 (4 Wochen u. früher)	Okt. 1970 (4 Wo.)	Okt. 1972 (4 Wo.)	Okt.73 (4Wo.)	Apr.74 (4 Wo.	April 1974
1.3 Kreis der Befragten	Tbk-Fürsorgestellen der Gesundheitsämter	Gesundheitsämter		ausgewählte Rehabilitationsträger	Rehabilitationsträger	Versorgungsämter	Polizeibehörden	Versicherungsträger		Gesetzl. Krankenkassen	Private Krankenkasse	Haushalte						
1.4 Auswahlsatz	entfällt											0,5 % (Bayern 1%)	0,5 % (Bayern 1%)	0,1 %	0,1 %	0,1 %	1 %	1 %
2. <u>Erhebungsmerkmale</u>																		
2.1 Medizinalstat. Merkmale																		
2.1.1 Erhebungsgegenstand	Prävalenz/Inzidenz	Inzidenz	Inzidenz	Rehabilitationsfall	Rehabilitationsfall	Prävalenz	Inzidenz	Inzidenz/Erstentschadtote Befufskrankheiten	Rentenzugang	Arbeitsunfähigkeitsfall	Leistung in DM	Prävalenz	Prävalenz/Inzidenz	Prävalenz/Inzidenz	Prävalenz U: Inzidenz			Prävalenz
2.1.2 Art und Ursache der Morbidität																		
2.1.2.1 Art der Krankheit	gesetzlich definiert			-	-	-	-	-	ICD	Diagnoseschlüssel: Soz.vers. träger 4)	Hamburger Diagnoseschlüssel 3)	-	Diagnoseschlüssel: Soz.vers. träger 4)	Diagnoseschlüssel in Anlehnung an ICD				
2.1.2.2 Art der Unfallverletzung	-	-	-	-	-	-	nach Schweregrad	-				-						
2.1.2.3 Unfallkategorie	-	-	-	-	-	-	-	+	-	+	-	+	+	+	+	+	+	-
2.1.2.4 Art der Behinderung	-	-	-	ICD	evtl. modifizierte ICD		-	-	-	-	-	+	-	-	-	-	-	+
2.1.2.5 Ursache der Behinderung	-	-	-	+	+	+	-	-	-	-	-	+	-	-	+	+	+	+
2.1.3 Dauer der Erkrankung	-	-	-	Rehabilitationsdauer		-	-	-	+	A.-Dauer	Krankenhausverweildauer	+	+	+	+	+	+	-
2.1.4 Art der Behandlung	-	-	-	+	+	-	-	-	+	+	-	+	+	+	+	+	+	+
2.1.4.1 stationär	-	-	-	+	+	-	-	-	+	+	-	-	+	+	+	+	+	Anstalt
2.1.4.2 ambulant	-	-	-	-	-	-	-	-	+	+	-	+	+	+	+	+	+	+
2.1.5 Sonstige Merkmale	-	-	frühere Erkrankungen	Ergebnis der Reha.-Maßnahmen, MdE		-	-	MdE	-	-	-	MdE		Bettlägerigkeit				
2.2 Bevölkerungsstatistische Merkmale																		
2.2.1 Alter	+	+	+	+	+	+	+	+	+	+	- (Kinder)	+	+	+	+	+	+	+
2.2.2 Geschlecht	+	+	+	+	+	+	-	+	+	+	+	+	+	+	+	+	+	+
2.2.3 Familienstand	-	-	+	-	-	evtl.	-	-	+	-	-	+	+	+	+	+	-	-
2.2.4 Familiengröße	-	-	-	-	-	-	-	-	+	-	-	+	+	-	-	-	-	+
2.2.5 Staatsangehörigkeit	+	-	-	-	+	+	-	+	-	-	-	-	-	-	-	-	-	-

2.3 Erwerbsstatistische Merkmale																		
2.3.1 Erwerbstätigkeit	-	-	-	+	+	+	-	+	+ A	-	-	+	+	+ A	+ A	+ A	-	-
2.3.2 Stellung im Beruf	-	-	-	+ Umschulungsmaßnahmen	+	+	-	-	-	-	-	+	+	+	+	+	-	-
2.3.3 Wirtschaftszweig	-	-	-	-	-	-	-	-	+	-	-	+	+	+	+	+	-	-
2.3.4 Einkommen der Haushalte	-	-	-	-	-	-	-	-	-	-	-	+	-	-	-	-	-	+
2.4 Regionale Merkmale	Kreise, Regierungsbezirke, Länder, BRD		Gesundheitsämter, Großstädte, Reg.-Bezirke, Länder, BRD	BRD	BRD evtl. Länder	BRD Länder	Gemeinden, Kreise, Reg.-Bezirke, Länder, BRD	BRD	Bereiche der Versorgungsanstalten, BRD	BRD	BRD		Länder, BRD					
3. Aufbereitung	Statistische Landesämter			Rehabilitationsträger	Stat. Landesämter Statistisches Bundesamt		Statistische Landesämter	Versicherungsträger		Gesetzliche Krankenkassen	Private Krankenkassen		Statistische Landesämter					
4. Auswertung	Statistische Landesämter, Statistisches Bundesamt	Bundesgesundheitsamt		Reha.-Träger Bundesarbeitsgemeinschaft Reha. Stat. Bundesamt	Statistisches Bundesamt		Stat. Landesämter, Stat. Bundesamt	Versicherungsträger BMA	Dt. Rentenversicherungsträger	Gesetzl. Krankenkassen, Bundesverband der AOK	Bundesverband der privaten Krankenkassen		Statistisches Bundesamt / Statistische Landesämter					

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1) Ohne die Statistik über erkennbare Fehlbildungen bei Geborenen (bisher unveröffentlicht).
2) Die Gesamtstatistik der Rehabilitation wird langfristig abgelöst durch die Statistik der Rehabilitationsmaßnahmen.
3) Diagnoseschlüssel der Sozialversicherungsträger (1962).
4) 2-stelliger Diagnoseschlüssel, in Anlehnung an die ICD.

Abkürzungen

m = monatlich
v = vierteljährlich
hj = halbjährlich
j = jährlich

A = Arbeitsunfähigkeit
K = Kranke Personen
MdE = Minderung der Erwerbsfähigkeit
U = Unfallverletzte Personen

TABLE 7.1 *Details of national statistics, and statistics from ministries and insurance bodies, currently published in the Federal Republic of Germany.*

consultations, and the advantage taken of preventive and early diagnostic methods.

It is also desirable that the surveys should appraise the significance of ill-health for the other members of the families of sick persons.

For 1976, the questionnaire used in 1973/74 is to be retained.

Experiences with early surveys

Timespan of the surveys. The initial survey in 1966 distinguished between diseases and injuries from accidents. The interviewees were asked to report disease on 1 and 30 April, and during April; whereas for injuries, the reporting period was the previous three months. The effects of memory failure and the telescoping of events were apparent in the results for injuries. In 1970 therefore, both reporting periods were set at one month; the disease morbidity was reported for the day of enquiry as well as 1 and 30 April, and for injuries, data were collected for any one day in the four-week period. The time concept was again altered in 1972 so that data were recorded for the day of enquiry and the previous four weeks; this was retained in 1973 and 1974.

Response rates. The surveys have been entirely voluntary: the response rate has, however, been good. The maximum refusal rate in any of the surveys was 1.1 per cent.

Diseases recorded. In 1966, records were made of all diseases reported, but only the most serious disease and injury was covered in any depth. In 1970, acute and chronic diseases were recorded separately, but in 1972 only one 'most serious' disease was covered, although whether it was acute or chronic was established. The types of disease, injuries due to accidents, and disabilities are recorded in written form on the questionnaire, and coded later. In 1966 the disease coding was a simple 2-digit classification used by the social insurance agencies, but from 1970 onwards a classification, based on the ICD, developed specifically for population surveys has been used.

The injuries due to accidents have been classified as:

(i) bone fractures, including fracture of the skull,
(ii) internal injuries, including brain damage,
(iii) deep open wounds,
(iv) burns,
(v) poisonings.

Injuries are also classified on a functional basis. Since no comparable international classification exists, the following categories have been defined for use in Germany:

(i) accident at work and on duty (excluding journey to and from work);
(ii) accident at school or training (excluding journey to and from school);
(iii) traffic accident, or accident during journey to and from work/school;
(iv) accident occurring at home;
(v) accident at sports/play ground.

7.5. Problems of population health surveys

The problems of population random samples can only briefly be indicated here. Many problems result from the fact that on the one hand questions are put to lay people, while on the other hand the interviewers are also lay people.

Thus, the decision as to whether or not a disease is present, is made by a lay person, and depends on subjective judgements. With certain diseases, there is always an unwillingness to supply information; tuberculosis, for instance has been, up to now, under-enumerated. Another source of incorrect answers is the fact that physicians do not always explain the nature of the illness to their patients, for example, malignant growths. The accuracy of statements is further reduced by the fact that the interviewed person gives information not only about his/her own disease, injury, or disability, but also about those of the other household members.

The results of enquiries are recorded by medically untrained interviewers, which is another potential source of error. Whether and to what extent the results are affected by the interviewers' technique of questioning, whether and to what extent their own subjectivity plays a role, requires further thorough investigation. Such surveys could possibly be supplemented by random spot checks by medical doctors, which would monitor not only the accuracy, but also the completeness of lay information.

The selection of the diagnostic code, which may be a matter of subjective judgement by the coders, is a further source of errors. The sampling fraction in 1970, 1972 and 1973 was 0.1 per cent. As a consequence many diagnostic categories were under-represented, and could not be included in the published statistics, because of sampling errors. This particularly concerned the relatively small number of persons injured in accidents, where the analyses by age, sex, nature of injury and accident category were rendered invalid; nor in many cases was it possible to link disease types with corresponding socio-economic data. The comparisons over time of certain survey characteristics were similarly restricted. The evaluation of the 1 per cent sample taken in 1974 will show how much significance to attribute to quantitative changes in the earlier surveys.

Paper 8

Health surveys in Ireland

G. Dean

8.1. Summary

This paper gives a brief outline of the organization of health services and statistics in Ireland and describes some of the routine statistics and surveys which have been in existence for some time. It touches on the role of the university medical schools in this field and then covers in detail the setting-up, and structure of the Medico-Social Research Board, and the surveys with which the Board is involved.

8.2. Introduction

Until the introduction of the National Health Service in Britain in 1948, the provision of health services in the two countries was very similar–except that those in Ireland were not so well-financed or organized. Although Ireland still does not have a national health service as such, the scope of the services provided by the State has increased over the 30 years, and the situation now is roughly mid-way between the British NHS and the free enterprise system of the USA.

Historically the local health services were the province of the Medical Officer of Health of each of the 26 counties of the country, and this fragmentation has led to the maintenance of services, and their associated statistics, which are of less importance today. However, the Republic has been divided into eight Health Board areas, and these Boards with their community physicians are now responsible for most of the routine surveys.

8.3. Traditional services and surveys

Infectious disease control

Surveillance of infectious diseases remains an important part of the community care programmes. Its effectiveness depends upon prevention, notification, diagnosis, and treatment; and a considerable body of supporting law has been built up, particularly in the Health Acts of 1947.

There are annual programmes of smallpox and, recently introduced, rubella vaccinations; diphtheria and poliomyelitis immunizations; and most especially BCG vaccination which has almost 100 per cent coverage. Tuberculosis was formerly the most serious health problem in Ireland and the Mass Miniature Radiography Board's mobile units offered free chest X-rays. However, the incidence has been reduced to less than 1 000 new cases per year, and deaths to about 200 per year and the X-ray screening has been stopped, although the legal requirement for the Department of Health to be notified of all new cases remains.

The Health Boards undertake screening programmes; screening for cancer of the cervix is carried out in some hospitals; and all newborn babies are screened for phenylketonuria through one national centre. In addition the privately organized Irish Heart Foundation undertakes medi-scan screening of 'at risk' groups for the early detection of ischaemic and other forms of heart disease.

Data are collected on all these activities and special surveys undertaken.

Supervision of food and drugs

The National Drugs Advisory Board was established in July 1966 and monitors newly introduced medicinal products to check their safety for human use. The Drugs Advisory Board makes full use of similar institutions which have developed in England and the United States. Surveys of drug abuse are also undertaken by the Drugs Advisory Board. The main drug problems in Ireland are the excessive use of tranquillisers and, of course, alcohol and nicotine.

General practitioner surveys

General practitioners in Ireland provide services for the less well-off on a fee per item of service basis, which are funded by the State. The remainder of the population pay the general practitioner privately. The College of General Practitioners in Ireland undertakes surveys on the use of the house doctor services by the public.

Maternity and infant care surveys

Most birth deliveries in Ireland take place in hospital, over one-third of them at the three internationally famous Dublin maternity hospitals. Excellent surveys of the infant and maternal morbidity and mortality are undertaken by the maternity hospitals. Other surveys are undertaken by the Health Boards which in some instances organize medical examinations by general practitioners.

Child health surveys

These services are provided by the local health authorities under the control of the Regional Boards and include scheduled medical examinations at the ages of six months, one year, two years, and then at school. These services, in particular the dental services for children, are undermanned. There are only 600 dentists in practice in Ireland for a population of three million people. Much greater use could be made of ancillary services, for instance nurses and dental nurses to improve dental hygiene. Fortunately, much of the water in Ireland is fluoridized.

8.4. The universities

The Republic of Ireland has four University medical schools, Trinity College and University College in Dublin, and the medical schools at the Universities of Cork and Galway. There is also the medical school at the Royal College of Surgeons of Ireland. Medical surveys are undertaken by the departments of medicine and of social medicine of the medical schools. To mention some examples the Department of Social Medicine at Trinity College is producing a geographical survey atlas of the distribution of all causes of death in the Republic. The Department of Social Medicine, University College, Dublin, has undertaken surveys of doctors' smoking habits and of anencephaly. The Cork medical school surveys on multiple sclerosis and Galway on coeliac disease.

8.5. The Medico-Social Research Board

In 1965 Professor Henning Friis of Copenhagen visited Ireland to study medico-social research and surveys in Ireland, and on his recommendation the Irish Government founded the Medico-Social Research Board. The Board consists of a Chairman and twelve Members who are chosen for their outstanding ability and give their services without payment. The Members represent the main medical and social medicine interests of the country, and they include two professors of social medicine, an obstetrician, a cardiologist, a professor of sociology, and the Chief Medical Officer of Health: seven of the twelve are medically qualified. The first Chairman, Professor Patrick Lynch, was an economist, and the present Chairman is a professor of business administration. The Board is largely independent of the State, although to a great extent financed by it. The Director is responsible to the Board and decides with them the major research projects, which are limited to those considered of medico-social importance to the country.

The Board organizes its own projects, appointing research supervisors on contract. Ireland also has a Medical Research Council which commissions research on a grant-giving basis, but its interests lie more with pure scientific research, and its objectives have not conflicted with those of the Medico-Social Research Board.

When the Board started its work in 1968, it considered that its first function was to provide information services based on:

(i) causes of death;
(ii) hospital admissions;
(iii) psychiatric hospital admissions;
(iv) special surveys of groups at risk such as children and the aged.

Surveys on the causes of death are not the concern of the Workshop Conference.

Hospital In-Patient Enquiry

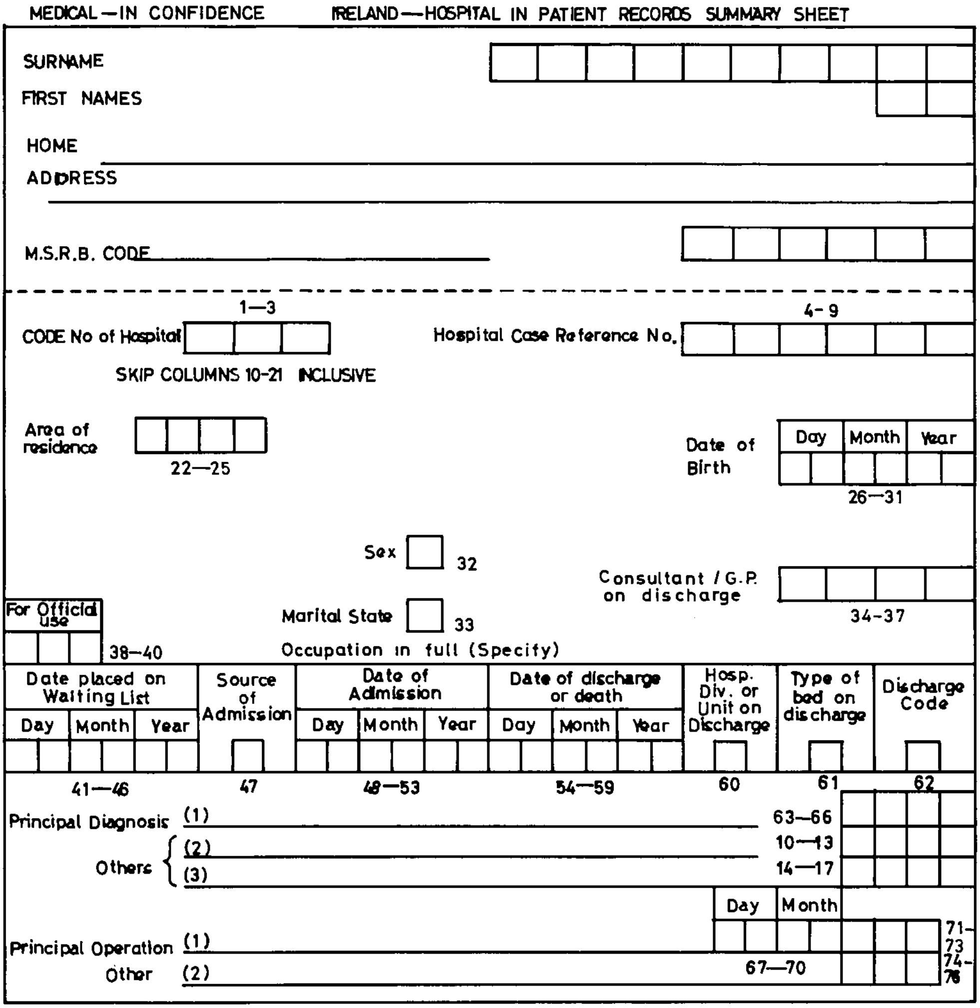
The Hospital In-Patient Enquiry (HIPE) Scheme in Ireland was founded on the scheme that was already functioning extremely well in Scotland, and we were fortunate in being provided with a great deal of assistance from the Scottish service, including their computer programs. The scheme was developed on a voluntary basis and all hospitals were asked to complete a simple form (Fig. 8.1) at discharge for all patients, which covers the following data: name; address; age; sex; main diagnosis and other diagnoses; main operations and other operations; length of stay; and disposal. These forms are collected by the Medico-Social Research Board, corrected, coded, and placed on computer tapes. The information from them is used to provide not only a diagnostic index for each hospital at national level but also detailed survey information on a number of other variables such as lengths of stay and results of treatment.

One problem which arose with the HIPE was confidentiality. Some hospitals objected to the scheme on the grounds that it was a breach of the confidential relationship between doctor and patient. This difficulty has been overcome in Ireland by using a two-part form; the main form, which alone is used for statistical data processing, is identifiable only by code number. However, the Director of the Board is entitled to keep the top part of the form which shows personal details. Thus, whilst confidentiality is maintained, these named portions of the forms can be used,when necessary, to separate the number of people admitted to hospital with any particular condition from the total number of admissions, and in this way makes it possible to undertake epidemiological research not only on hospital admissions but also on the number of persons with any particular condition who are admitted to hospital.

The HIPE provides an immense amount of information for surveys and, as evidence of this, the Board undertakes between 30 and 40 research projects each year based on this scheme.

Psychiatric reporting system

A survey of all admissions and discharges from Ireland's psychiatric hospitals, and a five-yearly census of psychiatric hospital patients is undertaken, under the supervision of Dr. Dermot Walsh, by the Medico-Social Research Board. The data collected in this reporting system and from case registers of patients who are seen outside hospital has enabled the Board to undertake a large



MEDICAL—IN CONFIDENCE IRELAND—HOSPITAL IN PATIENT RECORDS SUMMARY SHEET

SURNAME

FIRST NAMES

HOME ADDRESS

M.S.R.B. CODE

CODE No of Hospital ☐☐☐ 1—3

Hospital Case Reference No. ☐☐☐☐☐☐ 4-9

SKIP COLUMNS 10-21 INCLUSIVE

Area of residence ☐☐☐☐ 22—25

Date of Birth: Day ☐☐ Month ☐☐ Year ☐☐ 26—31

Sex ☐ 32

Consultant / G.P. on discharge ☐☐☐☐ 34-37

For Official use ☐☐☐ 38—40

Marital State ☐ 33

Occupation in full (Specify)

Date placed on Waiting List			Source of Admission	Date of Admission			Date of discharge or death			Hosp. Div. or Unit on Discharge	Type of bed on discharge	Discharge Code
Day	Month	Year		Day	Month	Year	Day	Month	Year			
☐☐	☐☐	☐☐	☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐	☐	☐
41—46			47	48—53			54—59			60	61	62

Principal Diagnosis (1) 63—66 ☐☐☐☐

Others (2) 10—13 ☐☐☐☐

(3) 14—17 ☐☐☐☐

Day Month

Principal Operation (1) ☐☐ ☐☐ ☐☐☐ 71–73

Other (2) 67—70 ☐☐☐ 74–76

FIG. 8.1 *Record sheet completed for every person who has received in-patient treatment on discharge from hospital.*

number of surveys on psychiatric problems in Ireland. As with the HIPE, it also provides administrators with data for administration of the services.

Other surveys

Other surveys that are being undertaken by the Medico-Social Research Board in co-operation with the Department of Health and the Universities include:

(i) WHO surveys on ischaemic heart disease and on stroke;

(ii) EEC surveys on the effects of the environment and, in particular, air pollution on the health of school children aged 7 to 11, and a proposed pilot survey on blood lead levels in Ireland;

(iii) surveys of the care of the aged in County Homes;

(iv) surveys on alcohol consumption and drinking habits;

(v) surveys on the number of mildly and severely handicapped in the country to be undertaken by Dr. Michael Mulcahy under the aegis of the Medico-Social Research Board in close co-operation with the Department of Health;

(vi) surveys on the functioning of psychiatric hospitals and on the reasons for admission to these hospitals;

(vii) studies on certification of births and deaths (some births and deaths are not certified in Ireland), and surveys on notification of stillbirths;

(viii) studies on abortions carried out on Irish girls in England;

(ix) surveys on suicide;

(x) studies on alcohol drinking habits among prisoners and the extent to which drinking habits cause habitual crime. These studies are being undertaken with the Minister for Justice and in collaboration with the Irish National Council on Alcoholism;

(xi) special *ad hoc* surveys, such as a survey of multiple sclerosis in Ireland, surveys of schizophrenia in certain communities, surveys on coeliac disease.

Poverty

The Medico-Social Research Board has held a number of seminars with the Director of the Economic and Social Research Institute of Ireland and Directors of other State Boards on the many problems associated with poverty in the Republic of Ireland, where over 10 per cent of the working population are unemployed. The Commission on Social Affairs of the EEC are now supporting a number of surveys of the factors associated with poverty through the Irish Department of Social Welfare. Currently, the Minister of Health in Ireland is also the Minister for Social Welfare.

8.6. Conclusion

Ireland perhaps has a very original idea to offer the other countries of the Community in the concept of a Medico-Social Research Board dedicated to studying and surveying the medico-social problems of the land. It is interesting, in fact, that this concept arose from a visit to Ireland, at the request of the Irish Government, of a Professor of Social Medicine of another member state of the Community, Denmark. A semi-independent national medico-social research institute which can undertake surveys and research and describe the results of its studies without being part of the Department of Health has great social and political advantages.

Paper 9

Present status of health surveys in Italy

C. Vetere

9.1. Summary

This paper discusses some of the problems in the field of health statistics in Italy at present, and the recent decision to establish a system of epidemiological research units under the coordination of the Instituto Superiore di Sanità. It describes the statistics on morbidity rates published by the national health insurance fund (INAM), and the hospital discharge statistics from the Central Institute for Statistics (ISTAT). It continues with descriptions of national and regional *ad hoc* surveys of particular interest, and concludes with comments on some aspects of the usefulness of health information.

9.2. Introduction

There is currently little which could be described as a national health information system in Italy. The flow of information from the sources which do exist is slow, and there is a general plaint about the scarcity of data; although this is not always based on any clear knowledge of the real utility of further statistical output.

In the field of classical infectious diseases, a Bill was introduced to finance, through the Instituto Superiore di Sanità, the coordination and promotion of units, to carry out epidemiological surveillance and data research, and to produce epidemiological 'intelligence'. It would be preferable for their terms of reference to be broadened to encompass chronic diseases and disability.

There is a danger that, because of the lack of general data, a multitude of specialized registers for single diseases, particularly cancer, will be established.

9.3. Currently available statistics

Morbidity statistics

The INAM 'Statistical Yearbook' includes morbidity data for two years, and for a group of 279 causes corresponding closely to the ICD (3-digit); it is published with a delay of two-three years. It gives province of residence, sex, age, civil status, occupational category (analysed not by the five class system, but by a more complicated list of occupations), duration of the disease and of the associated hospital stay; and the frequency of admission to hospital (per 10 000) for the insured population, by occupational category. It is not possible to distinguish repeat admissions of persons suffering from chronic or recurrent diseases. The data give useful information about the incidence of some acute conditions; allow a calculation of death rates for some diseases; and point to some interesting differences between occupational groups. Lack of detailed data on the age-composition of the insured population severely limits the use of these statistics for comparisons and for extrapolations to the general population; this is especially unfortunate since INAM covers half of the total insured population so that the base for these statistics is some 20 million people.

Hospital discharge statistics

The hospital discharge sample is the responsibility of the ISTAT. The statistics are based on data collected on the patients discharged in the first 7 days of every month by a sample of 25 per cent of Italian hospitals. They are published every 3-4 years since there are no great variations between adjacent years. The statistics cover items in the ICD (8th revision) and give an analysis of the age/sex distribution of patients and average length of stay for every cause. Again, repeat admissions cannot be identified. The scarcity of structural data on hospitals leads to difficulties in the choice of the sample; number of beds and specialities are the only routinely known characteristics. In addition, the accuracy of the returns varies between the hospitals in the sample, and this throws even more doubt on the validity of the statistics.

Psychiatric hospitals

This survey also covers psychiatric patients, and here it is possible to separate first admissions from total admissions. Some difficulty is presented by a new law which allows voluntary admittance to psychiatric hospitals. Sometimes there are short-stay admissions, with discharge under the label 'not requiring psychiatric confinement', although the majority of this type of patient are alcoholics or drug-addicts. A special study is under way, during which a tentative diagnosis will be recorded (without administrative implications) for a sample of around 10 per cent of the whole patient flow.

9.4. *Ad hoc* surveys

1957 Morbidity survey

In 1957, the ISTAT carried out a health interview survey which collected data on diseases and disability experienced in a one-week period. The survey covered 49 191 people, a stratified sample which was normally used for a periodic enquiry on unemployment. During the period of the survey, Italy was in the grip of the famous 'Asian flu' epidemic, so the data were analysed eliminating the self-declared cases of influenza. Reliable and interesting information was obtained on the prevalence of blindness (1.2 cases per thousand), deafness (0.9 cases per thousand), and crippling conditions of the limbs (7.2 cases per thousand). The observed prevalence of mental disorders (3 cases per thousand) is most probably lower than the real level: and the same socio-cultural reasons may explain the low prevalence of cancer (0.8 cases per thousand). It must be pointed out that in spite of the involvement in the survey of Public Health Officers, no real clinical control on a sub-sample was performed, and the training of the interviewers was rather superficial. However, the survey is noteworthy as one of the few European health surveys at that time. Financial difficulties and scepticism of the usefulness were the main reasons for the fact that no further such surveys have been undertaken.

Study of the health of rural children

This study was funded by the 'Sickness fund for agricultural smallholders'. In 1966, data were collected in four regions on a cohort of 1 716 children born in 1961. The random sample was representative of the total rural population of children. The study involved the preparation of full medical histories and complete medical examinations, covering all the anthropological data, blood and urine tests, radiological examination of the wrist, and (for a sub-sample) psychological and behavioural tests. The study was repeated on a nationwide sample in 1972-73.

Survey of handicapped persons

A survey of handicapped persons under the age of 32 years was carried out by the Institute of

Sociology in Trieste, using social workers and volunteers. They collected data from rehabilitation centres, special schools, and hospitals, but also used all the existing sources, such as the files of the association of crippled persons, the files of private and public social care institutions, municipalities, and so on. An evaluation was made of the degree of disability related to age, and school performance or working capacity. The results can be used to calculate minimal necessary rehabilitation services. It is unfortunate that very few copies of the report of the survey were published so that many experts have no knowledge of it.

San Marino health census

San Marino is developing a total health census of its 18 000 inhabitants, with prospective continuous research, as part of a newly established comprehensive service, which includes preventive measures within the remit of the health centres. Observed prevalence rates are: cancer, 13 cases per thousand; diabetes, 29 cases per thousand; arthritis, 140 cases per thousand; and coronary heart disease, 22 cases per thousand. The existing network is aimed at the identification of other risk factors for heart diseases and diabetes.

9.5. New developments in health information

There are several partial health surveys planned or beginning, such as the evaluation of the degree of invalidity amongst the 52 000 handicapped people cared for in special institutions financed by the Ministry of Health; and the current census of health personnel in all the public and private health establishments, with particular regard to the age, professional and motivational composition of the Sickness Funds' staff who should merge into the future National Health Service.

The new laws on the rights of workers giving to workers' associations the possibility of controlling the working environment, and of agreeing with external medical services on the need for special studies. Several surveys have been carried out through the cooperation of Trade Unions and the local Institute of Hygiene and Preventive Medicine. It is interesting to note that in many cases the list of questions included in the questionnaires on health, and working and living conditions has been drawn up and amended by the same workers who volunteer to participate in these surveys. One of the most complete lists (about 500 items) is regularly administered in the Pignone Factory of Florence under the responsibility of the Provincial Institute for Preventive Medicine. Industrial diseases cannot, however, be restricted to the typical occupational illnesses; also relevant are the influences of long-distance commuting, living conditions, family structure and so on.

Research is also being undertaken on the value of new epidemiological or structural data systems, with due regard to the danger of producing a lot of numbers not fully understood by administrators. One of the more important steps should be the training of administrators, and a most valuable side-effect of the merger between the health and social services will be the introduction of modern statistical knowledge into upper management levels. The attitude towards major methodological problems in the field of health surveys (such as the training of interviewers) also seems to be more positive among experts in the social services. At the same time, it becomes more and more evident that social and economic data can be more important for the evaluation of health status than vital data, and that the results of mortality and morbidity surveillance of veterinary services and of agricultural inspection services could also represent an important monitoring system.

Paper 10

Health surveys in the Netherlands

J.W.H. van der Berg and M.W. de Kleijn-de Vrankrijker

10.1. Summary

This paper describes the current decentralized health care and health information systems in the Netherlands and, in a detailed appendix, lists the information available. It discusses the shortcomings in the health information, especially the lack of national survey data, that have resulted from this decentralization; the growing awareness of the need for improvements in health information; and methods by which these needs could be met. It goes on to give details of the National Health Interview Survey which is being planned, and for which data collection should begin in 1977.

10.2. Introduction

The initial bulletin concerning this Workshop Conference stated that systems discussed should cover a broad range of morbidity and health information; be national or regional in coverage; and be continuous over a long period of time. In the Netherlands, there have been surveys on a specific disease, or covering small areas or short time-spans, but until recently, only two which met the necessary conditions had been carried out. The Living Situation Survey (LSS) 1974 (Netherlands Central Bureau of Statistics 1975) covered many aspects of the way of living, including health; it will be repeated periodically. The Survey of Physically Handicapped Persons (Netherlands Central Bureau of Statistics 1974) was an *ad hoc* survey.

10.3. The current state of the organization of health care and health statistics

The Netherlands has a high standard of living, and according to world comparative statistics, its public health is good. However, the health care system is very decentralized. There are many health institutions which have come into being through private enterprise, and each one has its own territory.

Similarly, the collection, processing, and dissemination of statistical information is performed by many institutions and organizations. Nevertheless, the statistical information is of a reasonably high standard. It is mainly based on a 100 per cent population registration system, and registrations of causes of death, hospital diagnosis, industrial accidents, causes of sickness absenteeism, working incapacity, and the manpower, facilities, costs and financing of health services. Details are given in section 10.7. Appendix.

There has been no pressure for a national health interview survey, even though more and better information would be desirable. There has certainly been no inclination to start health examination surveys on a large scale, except in the fields of surveillance and control of diseases, such as tuberculosis and carcinoma of the cervix, and physical fitness. There has also been some debate as to which of the diverse institutions involved in the health statistics system should carry out a national survey—although cooperation between them has been increasing recently.

10.4. Shortcomings of the present system

The available statistical information does not cover all aspects of public health care for all population groups. With some rare exceptions, data are lacking on the incidence and prevalence of diseases in the total population, and on the out-patient care of psychiatric patients. Again, details are given in section 10.7. Appendix.

The greater part of the existing statistical information covers discrete events and their treatment, and this makes it next to impossible to gain insight into the flow through the stages of chronic diseases and the different forms of health care. There is also no linkage of data on health status and health care usage, nor can these two types of data be linked with those on social characteristics and other variables that have an influence on health. It is obvious also that the diversity of agencies and institutions engaged in the collection and processing of statistical data does not simplify the making good of these deficiencies.

There are several reasons for the increasing awareness of the shortcomings.

(i) There has in the last few years been an increasing demand for information to aid management to improve the effectiveness and efficiency of health services, and to check increasing costs. The most important need is for information about just those relationships that the present statistical system does not cover.

(ii) Disease is becoming less and less a purely medical concern. Increasing notice is given to the chronic diseases, which although not currently curable, consume a large proportion of health resources; and also to the discomforts, symptoms, and illness which cannot as yet be attributed to specific diseases. The realization is growing that social factors play an important part, and that perceptions and satisfactions must also be considered. As a result, non-medical professionals are taking up positions in the health care system.

(iii) In addition, there is an apparent tendency, partly stimulated by the computer, towards wanting to know 'everything about everyone'.

10.5. How can the data for integrated information be obtained?

Starting from the consideration of existing and planned, mostly independent, statistics and the specified deficiencies, there are broadly three approaches to producing integrated information and to filling the gaps.

New registrations and record linkage

Automatic data processing offers new possibilities for existing and new registration systems, and has ensured considerable qualitative improvements in statistics. The continued tendency towards extensive general automated data banks is mainly based on administrative and policy requirements, for control, surveillance, treatment, reimbursement, and so on.

In the short, and probably also in the long term, the possibilities of (medical) record linkage seem likely to supply only partial and/or limited answers to fill the current gaps. This is *inter alia* caused by differences in objectives, definitions, classifications, and populations covered, between the many organizations involved; the limited number of variables which can be cross-linked; comparative inflexibility; and considerably higher costs of input and output.

Health interview surveys

Surveys could provide data to bridge many of the gaps in the information system so that it would become possible to follow the flow of patients and to establish relationships between the different data systems (public health, health care and other factors).

Epidemiological studies

As might be expected the existing, non-integrated health statistics system does not offer an adequate basis for exhaustive epidemiological studies; an integrated system would provide a better framework. It would be expedient to coordinate epidemiological research in such a way as to provide a better insight into the data resulting from the health surveys and into the variables of the integrated statistical system, so that the results could contribute substantially towards the development of better data and statistics.

10.6. Developing the health statistics system

The decision has now been taken that a national health interview survey should be initiated, and that it should be organized by the Central Bureau of Statistics (CBS), which is the central government authority in the field of statistics. Its independence and objectivity are not only generally accepted, but are in fact protected by law to a large extent. The Central Statistical Commission has approved the project, and funds were included in the CBS budgets for 1975 and 1976, and in forward planning for 1977-81.

The first LSS and the Survey of Physically Handicapped Persons have been taken as preliminary trials, and the planning of the actual Health Interview Survey is underway; discussions are taking place with government institutions, scientists, and planning offices. A plan of operations should be completed shortly and it is hoped that field work will begin in 1977.

The survey will be based on random population sample, and will consist of routine collection of basic data, supplemented by periodic collection of data relating to specific aspects of health or health care, or to specific population groups. The interviews will be based on questionnaires with as many of the questions as possible being 'closed questions'. The data collected will cover:

(i) health–in such a way that the data can be correlated with existing statistics. In addition to data on diseases, the questions will cover implications, such as disability and dependency, and subjective aspects, perceptions of and satisfaction with the care received, for instance;

(ii) health care usage;

(iii) economic, social, environmental, and other factors;

(iv) the relationships between (i), (ii), and (iii).

The widest possible scope will be given to the use of social indicators; and the surveys may contribute to developments in this field.

10.7. Appendix; summary of available health statistics

Subject	Coverage	Periodicity
Births		
(i) General data, including	all births	continuous registration
- age of mother and parity - place of birth and obstetrical assistance - live and foetal births		

Subject	Coverage	Periodicity
(ii) Other data		
- hospital deliveries	all hospital deliveries	annual data/continuous registration
- home deliveries	practically all home deliveries	annual general data
Morbidity		
(i) Health surveys	samples	3 sample surveys per year are planned, of which one is intended to be a continuous health interview survey
(ii) Health examinations		
- tuberculosis and neoplasms of lung	total population	periodic, voluntary
- general fitness	conscripts, civil servants, etc.	continuous, compulsory
(iii) † Special registrations		
- road traffic accidents	total population	continuous, compulsory
- infectious diseases	total population	continuous, compulsory
- some other very specific registrations	total population	continuous, compulsory
(iv) † Registrations in the economically active population		
- sickness absenteeism	all employees, excluding most civil servants	annual, compulsory
- industrial accidents and occupational diseases	all employees, excluding most civil servants	annual, compulsory
- working incapacity (will be extended to the total population by the end of 1976)	all employees, separate system for civil servants	annual, compulsory
(v) Registration by general practitioners - some infectious diseases and family planning methods	sample of general practitioners	continuous system, voluntary
(vi) Morbidity registration in institutions		
- general, university and specialized hospitals (diagnosis, operations, duration, etc.)	about 75 per cent of hospitals	continuous system, voluntary
- mental hospitals (idem)		
- nursing homes	all homes	every five years
Mortality		
Causes of death	all deaths	continuous, compulsory
Health resources		
(i) In-patient care	all institutions hospitals	annual survey monthly
- manpower		
- financing		
- investments		
- admissions, discharges, duration of stay, etc. (no diagnosis††)		
(ii) Out-patient care†††	all types of clinics and services	normally annual survey, compulsory
- manpower		
- financing		
- visits		

Subject	Coverage	Periodicity
(iii) Compulsory sickness insurance		
Data about referral diagnosis, reason for admission and types of 'medical' and dental treatment	70 per cent of population	annual

† These registrations provide statistics according to diagnosis, duration, etc.
†† For information on diagnosis and 'medical' treatment see *Morbidity* (vi).
††† Excluding visits at general practitioners, specialists' practices and dental surgeries.

10.8. References

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Paper 11

Health surveys in the United Kingdom

F.E. Whitehead

11.1. Summary

This paper describes information obtained in Britain from three sample surveys.

The Hospital In-Patient Enquiry (HIPE) is the continuous system for the production of national statistics on hospital usage. A 10 per cent sample of data collected within health authorities for management purposes, is centrally processed to provide statistics on factors such as length of stay, diagnosis, and surgical procedures, for every discharge (including deaths) from hospital, excluding psychiatric and maternity cases.

The Second National Morbidity Study was carried out in 1970/71. A sample of general practitioners maintained survey records, for a one-year period, on all episodes of ill-health presented by their patients. This enabled measures of morbidity rates, referral rates, and so on linked to medically defined diagnoses to be obtained. Mention is also made of the available analyses of prescriptions issued and the drugs prescribed, which are produced by the Prescriptions Pricing Authority.

The General Household Survey (GHS) is a continuing survey of a sample of households in the UK, which collects data on a wide range of demographic and socio-economic variables, as well as on many aspects of ill-health, and health service usage.

11.2. Introduction

This paper deals with health information derived from sample enquiries. It largely ignores the vast amount of data available from medical records by way of routine 100 per cent data collection for operational and management purposes. Three main areas are covered:

(i) the Hospital In-Patient Enquiry (HIPE)—as the main example of a routine sample enquiry of discharges from the deaths in non-psychiatric hospitals;

(ii) the National Morbidity Study 1970/71—an *ad hoc* study of morbidity encountered in a sample of general practices over the course of a year; and

(iii) the General Household Survey (GHS)—in which data on self-reported morbidity is collected.

11.3. The Hospital In-Patient Enquiry

Base line data on hospital activity is provided in summary form by hospitals in an annual hospital return relating to the calendar year (SH3); a much shorter return provides certain key items of information at the mid-year. The annual return is the main source of data on available hospital beds, occupied beds, discharges and deaths of in-patients, average duration of in-patient episodes, waiting lists, day cases, new out-patients, total out-patient attendances and certain derived measures for each of some 40 categories of hospital specialist departments. Statistics are also provided on the activity of maternity departments, radiological departments, and a wide range of non-consultative hospital departments such as occupational therapy, electrocardiography, surgical appliances, and dietetics, to name some of the major ones. Apart from the main hospital return, there are a variety of others dealing with particular aspects of hospital work in greater detail, for instance, pathology laboratories, radiological departments, renal dialysis units, clinics for the treatment of sexually transmitted diseases, blood transfusion units, and services for the deaf.

These statistics have the strengths and weaknesses of data based on 100 per cent counts, that is they are available quickly, and in the main consistently, for all areas of the country, but contain no information on the characteristics of the patients in terms of age, disease or treatment, and so provide only broad measures of changes in provision and activity. They have, therefore, to be supplemented by statistics based on the more detailed analysis of individual cases.

For over 20 years, analyses of the characteristics of a sample of patients discharged from non-psychiatric hospitals have been compiled and published in the reports of the HIPE. Discharges, including deaths, are analysed by age, sex, marital condition, length of stay, hospital department, diagnosis, operations, and these analyses provide a wide range of medical and administrative information for monitoring the work of the hospital service at national and regional level and for planning future developments. It has also proved useful for epidemiological enquiries.

Over the past ten years a comprehensive data collection and retrieval system, known as the Hospital Activity Analysis (HAA) has been introduced to cover all non-psychiatric non-maternity in-patient records. The objectives of the HAA are to provide health service clinicians and administrators with meaningful analyses relating to the care of in-patients to help them to make decisions on the use and allocation of health care resources; to provide clinicians with summarized information about their own patients, to produce administrative information on items such as waiting lists, duration of stay, and catchment areas, for regional and area authorities. Data collected include all the items for the HIPE, which, except in respect of maternity cases, is now derived as a 10 per cent sample of HAA. Thus detailed hospital in-patient statistics are derived from a management information system which makes use of the data at the same time as, if not before it becomes available for statistical analysis nationally.

The HIPE is now, apart from maternity cases, based on a sample of discharges and deaths covered by HAA. Each Regional Health Authority is responsible for HAA in its own region and submits the HIPE sample input on magnetic tape at quarterly intervals to the Office of Population Censuses and Surveys (OPCS) who are still responsible for the data processing for national purposes. This raises a number of problems. Since each region is responsible for coding, processing, validation of data, and selection of the HIPE sample it is important to obtain national consistency between regions. At present, there are slight differences in the method of sample selection, although these are not serious, but there are considerable differences in the way in which validation checks are carried out and how cases failing the tests are treated. The OPCS carry out standard tests on the input data received from each region and, despite the regional procedures, has to resolve many queries direct with regions.

Now that the coverage of HAA is almost complete, concern has focused on developing its uses and improving quality. Quality and use are connected since if hospitals find the data useful they will be motivated to improve the quality; conversely where quality of HAA is demonstrably poor, hospital doctors will be reluctant to use and trust it. Surveys are to be mounted in the near future to assess the usefulness of HAA to administrators and hospital doctors, and also to check the quality of the output by comparing the information for a sample of coded documents with the original data in medical records. It is the accuracy of disease and operation coding which is of critical interest.

The coverage of HIPE each year is checked against the total number of discharges and deaths reported by hospitals on the main administrative return (SH3). This latter source gives a breakdown of discharges and deaths by hospital department but not by diagnostic category. The grossing up factors for HIPE are constructed so that HIPE results agree with SH3 results at the national level for each speciality separately. From January 1974 HAA, and consequently HIPE, includes day cases although a uniform definition of a 'day case' has not yet been agreed between regional authorities. There are plans to extend HAA to maternity cases eventually; a trial scheme has operated for some years in certain hospitals and is now being evaluated. A small trial of a system for out-patient departments is taking place at one hospital.

The value of HIPE lies in its potential to describe treatment in non-psychiatric hospitals either in terms of hospital specialities, diagnostic categories, operations performed, or client groups such as children or the elderly. Its weaknesses are:

(i) the sample size is often insufficient for local studies or the investigation of a small speciality or client group at the national level;

(ii) there is space for only a limited number of diagnoses and operations so it is sometimes deficient in diseases and procedures which are usually subsidiary to a main one;

(iii) nothing is recorded on drug treatment;

(iv) there is no provision for linking successive periods in hospital of the same patient;

(v) its timeliness is vulnerable to computing problems in Regional Health Authorities and the OPCS. (The preliminary tables for 1972 were published in November 1973; the main 1972 report was published mid-1974. The 1973 report will however be nearly 12 months later than this).

To overcome these weaknesses, various alternative developments are being considered. The central processing of HAA is one possibility both as a means of improving timeliness of national statistics and the detail available centrally for individual hospitals and small national specialities. A small experiment is being undertaken to test the feasibility and usefulness of including information on drug administration in HAA. The Oxford Record Linkage Study has for many years been developing techniques for linking together information about successive hospital spells for the same people and applying the results in epidemiological enquiries and management studies.

11.4. Morbidity statistics from general practice

There are no routine statistics on the workload of general practitioners. Data on the number of people consulting general practitioners and their characteristics has therefore to be obtained by special sample enquiries. One approach in the UK has been by household survey methods in which samples of the general population are questioned about contacts with general practitioners, for example, in the Survey of Sickness (1943-52) and more recently in the health section of the General Household Survey. Although this method has many advantages, it is difficult to use it to obtain reliable data on the incidence of consultation over a long period of time and on the morbidity of those consulting. Such information is more reliably obtained from the medical records of general practitioners.

There have been two major national studies of general practitioner records in the UK. The first covered the period May 1955 to April 1956 (Logan and Cushion 1958), the second the period 1970 to 1971 (Office of Population Censuses and Surveys, Royal College of General Practitioners, and Department of Health and Social Security 1973). Both surveys were based on a sample of general practices and undertaken in close collaboration between the OPCS (formerly the General Register Office) and the General Practice Research Unit of the Royal College of General Practitioners. The basic method of these surveys was to persuade a sample of general practitioners to maintain special records for a full year of every NHS patient on his list showing age, sex, dates of consultation, diagnosis, and referral to hospital. In the 1955/56 survey reporting was confined to details of every consultation, except for a sub-sample of practices where the occupation of patients was also studied; for this sub-sample, details of the characteristics of all patients were required to provide denominators for consultation rates by occupational groups. For the 1970/71 study details of certain characteristics of all patients were provided to the OPCS in advance of the survey so that practice registers could be compiled and maintained to take account of births, deaths and movements into and out of the practice, as the survey continued. The register comprised such items as: doctor code; surname and forename of patient; date of birth; sex; marital status (for some practices); occupation (for some practices); address; National Health Service number; and date of entry to practice list.

These details were put onto magnetic tape by OPCS with the exception of the occupation, the address and the NHS number. Only the initial of the forename and first three letters of the surname were used, to safeguard the confidentiality of the personal information. During the course of the survey, therefore, the cooperating general practitioners informed OPCS of additions to and deletions from the practice registers established at the outset, thus ensuring that the individuals' 'period of risk' during the year was properly calculated for the appropriate population denominators.

An important aid in recording the details of consultations was the Diagnostic Index consisting of a ring binder containing a series of overlapping recording sheets so arranged that each sheet was aligned to a particular diagnostic category. The list comprising some 500 categories was condensed from the ICD. Each recording sheet was double sided; details of males suffering from a particular disease were recorded on the front while those for women were recorded on the back. Thus a record was made over a period of all people suffering from a particular disease. The diagnostic code was entered on the recording sheet and the details of individual episodes as they occurred.

In recording doctor-patient contacts a distinction was made between an 'episode' of illness and a 'consultation'. A consultation was defined as any face to face contact, either at the patient's home or at the doctor's surgery but telephone contacts and contacts with ancillary staff were not recorded. The term 'episode' was used to describe a period of illness in the course of which there may have been several consultations. The following data were recorded for each episode:

(i) data of first consultation within the survey period;

(ii) type of episode, that is episode starting prior to survey, new episode, recurrence of previously diagnosed condition, episode initiated outside the practice;

(iii) name;

(iv) date of birth;

(v) place and date of consultations;

(vi) referral to hospital out-patient clinic; for clinical investigations; for admission as an in-patient; to local authority social services; death; other.

Information on contacts was sent to the OPCS processing office every quarter.

Confidentiality of individual medical data was safeguarded in the computer system by the use of a limited number comprising the first three letters of the surname, the initial of the first forename, sex, and full date of birth. No names in the practice registers were retained in the processing office after coding and, although surnames were retained on the recording sheets, diagnosis was in coded form; only the identity numbers were used in computing.

The analyses prepared comprised mainly episode, consultation, patient contact and referral rates by age, sex and diagnostic category. Most of the tables referred to England and Wales as a whole but some regional tables were prepared. However, because of the small number of practices covered in each region comparison of regional rates requires caution. The report on the 1970/71 study draws attention to the tables which can be compared with those from the 1955/56 survey. Checks were carried out to assess the completeness of practice lists and morbidity recording. It is known that practice lists are somewhat inflated by the failure of patients to change doctors, if this is appropriate, as soon as they change address. A special check was, therefore, carried out on a small sample of people from each practice list for whom no morbidity was recorded. The object of the check was to ensure that these people were rightly included in the population denominators. As a result it was estimated that the practice lists were inflated by just over 1 per cent. A further check was carried out by comparing deaths recorded in the practice with the number expected on the basis of national age/sex mortality rates. The results gave an overall deficit of 25 per cent; but some of this was discovered to be due to the recording of deaths as withdrawals from lists. Taking into account the nature of the sample and the fact that deaths account for a small proportion of changes in lists it was not felt that the remaining deficiency was likely to account for any sizeable inflation of the study population.

To check the coverage and quality of morbidity recording a sample of 100 people was selected from each of the sample practices and a special enquiry undertaken to compare their morbidity experience by reference to the original clinical notes with the morbidity experience as revealed by the main study. This revealed a deficiency of 3.5 per cent in the consultations in the main study and nearly 12 per cent for referrals. On the other hand it was found that the main study records sometimes contained more information than the clinical notes! The quality of diagnostic coding was also checked since in the 1970/71 survey this was left to general practitioners; in the 1955/56 survey diagnostic coding was carried out centrally. The average practice error was found to be 5.6 per cent; 2.1 per cent in the 18 main sections of the classification used.

The 1955/56 and 1970/71 National Morbidity Surveys show that it is feasible to collect good quality data from a sample of general practices but the fact that the sample of practices covered was small and not randomly selected means that the results are not only subject to relatively high sampling errors but are also possibly affected by biases that it has not been possible to measure. It is unlikely for example that a group of general practitioners prepared to record morbidity in their practice systematically for a whole year will be typical of the generality of family doctors in their methods of working or in the characteristics of the practice population. However, the difficulty of obtaining valid data from a true probability sample of doctors is formidable. The study produced its most useful data at national level; regional output was of limited value because the number of practices covered in most regions was small. The quality of the data obtained compares very favourably with that from other surveys. No plans exist for a repetition of the 1970/71 national survey but a small scale study based on fewer practices has continued.

Prescription analysis

A sample study of some relevance to the work of general practitioners is the analysis of prescriptions. The majority of prescriptions for medicines and so on written by general practitioners are dispensed by retail pharmacies who are subsequently reimbursed for the cost of the drugs and pharmacy services by the Prescription Pricing Authority. There is a standard charge for each item dispensed but children, the elderly and certain other categories are exempt. Statistics on the number of prescriptions dispensed and the drugs issued against them are derived from a 0.5 per cent sample of all prescriptions priced by the Prescriptions Pricing Authority. With the total number of prescriptions running at just below 300 million in England and Wales, this sample size is adequate for most purposes nationally although as is to be expected it is somewhat inadequate as a source of data on drugs rarely prescribed, and on detailed sub-regional data.

Some data is produced for every item in the Department of Health and Social Security drug classification but for most purposes the data is summarized into therapeutic groups. There are disadvantages in this as many drugs have more than one therapeutic use and the summarized data can be misleading as a source of data on the total use of drugs. The analysis provides no data on the characteristics of patients or the diagnosis for which the prescription was written. Such data is collected by a market research firm, Intercontinental Medical Statistics, from a sample of general practitioners but the results are not available to the Department of Health and Social Security. The sample of doctors providing the data is a voluntary one and may not be representative of all doctors.

The results yield estimates of drugs dispensed but not of drugs consumed; there is some evidence from household surveys that some people do not follow their doctor's advice, treat themselves with medicines available without a prescription, or for a number of reasons never finish the course prescribed.

11.5. Household surveys

A general weakness of health statistics based on the use of hospital and community services is that they reflect the provision of services, and demonstrate the demand for them, but do not identify the need for them. Data on health care needs can be obtained objectively from screening surveys in which samples of the population are examined by medically trained staff to establish the prevalence of particular conditions and/or the need for specific services such as dental or optical treatment. In England and Wales the only comprehensive national studies that could properly be called screening surveys have been those enquiring into the state of adult (Gray, Todd, Slack, and Bulman 1970) and child (Todd 1975) dental health (see section 14.7 for more detail of these surveys). To a lesser extent, the nutrition surveys undertaken among special groups such as the elderly (1967/68 and 1973/74) and schoolchildren (1971), which included medical examination and biochemical tests as part of a general screening for malnutrition, also establish objective indicators of need for health care. But these surveys, although detailed, have tended to cover small samples for specific maladies. In general, surveys involving medical staff have proved to be too costly to mount on a national basis and have tended to be concentrated in a few localities. Moreover, there is reluctance to carry out screening surveys to identify specific diseases and conditions unless there are resources for the effective treatment of those found suffering from them and for the maintenance of that treatment thereafter.

These considerations, however, do not apply to household surveys aimed at identifying the prevalence of self-reported disease and the perceived need for health care. In 1969 a major survey was undertaken to establish the incidence of physical handicap and impairment among adults (Harris 1971). Estimates were prepared of the physically handicapped and impaired by nine categories of severity according to the extent to which respondents were able to care for themselves, for instance, eat, wash, dress with help. Although the measures obtained from this survey lacked the clinical detail that would have been desirable to establish the incidence of physical disablement objectively the results were, nevertheless, extremely useful for the development of services. Guidance has been given to local authorities on how to carry out similar surveys locally. Section 14.6 describes this survey in greater detail.

Since 1971, the GHS has run continuously seeking a wide range of information from a sample of about 15 000 households a year. The survey has covered such topics as health, the use of health services, self medication and smoking habits. The survey is covered in detail in section 14.8.

As a result there are now measures, based on self-reporting, of the prevalence of chronic illness and disability (defined as limiting longstanding conditions) and acute sickness (defined as conditions limiting normal activity in the two weeks prior to the interview). The survey also provides information on consultations with general practitioners, attendances at out-patient departments, and in-patient episodes. The value of the GHS is that it provides information on the characteristics of those receiving health care which are not generally available from statistics based on medical records, and some data on those claiming to be chronically or acutely ill and not currently in touch with health services. The GHS results to date have been useful in describing the distribution of self-reported chronic and acute sickness in the different regions and socio-economic groups. It has provided data on the characteristics of people using different parts of the health services that are not available from medical records. The inclusion of questions on smoking habits will allow for an analysis of the health and use of services of smokers and non-smokers respectively. Moreover it is capable of identifying people with multiple problems or who are heavy users of services. However, there is often little congruence between GHS data and data from other sources since response to survey questions can be biased by poor memory and inadequate knowledge of services received.

The social survey can obtain considerably more detail on the personal and household characteristics of persons who are sick or disabled and/or have used services than can ever be recorded reliably and consistently in medical records. It can provide data on the prevalence of conditions in, and the use of certain services by, particular client groups that are unobtainable from routine information systems. This holds out the hope that differences in the prevalence of disease and disability and use of health services between different social groups and local areas can perhaps be explained in terms of social variables. The search for the social determinants of health care needs by the statistical analysis of survey data has not been successful to date. This could be due to omission of relevant variables in the basic data and/or insufficient observations of sick people and health service users. Perhaps survey techniques should aim at obtaining more observations, by seeking data on health care needs and use of services over longer periods than at present, at the price of less accuracy, less comparability with data from routine health statistics. Experimental and pilot studies are in hand to test new methods.

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Paper 12

Health surveys in national health information systems

V. Ovtcharov

12.1. Summary

This paper discusses the various uses of health information, aspects which must be taken into consideration when systems are set up, and the contributions which the WHO has made to the methodology of health surveys. It goes on to describe projects on topics such as infant mortality and fertility, which have been undertaken with assistance from the WHO, and in particular studies of the requirements for information for planning health services. It gives details of health surveys carried out in several countries, putting emphasis on methodological aspects.

12.2. Introduction

Increasing demands for statistics in support of the planning and evaluation of public health programmes require the constant adaptation and development of health statistical information systems at all levels of health administration. National Health Statistics Information Systems (HSIS) should provide reliable multi-purpose descriptive health statistics for the use of the health sector as a whole, and, in particular, to meet the needs of governmental policy makers, managers and administrators of national health programmes.

Thus, health statistics systems should be developed according to the needs of users since otherwise the collection of statistics may become an inflexible routine procedure, obsolete and of little value to a progressive health service. First, a systems analysis of existing health services and of programmes which are either in the planning stage or already operating should be carried out. This will provide the necessary basis for the assessment of health information needs. It is felt that essential information for dynamic health planning and management might be obtained by a careful combination of the traditional reporting system and a well-developed national health survey organization. Within the information system, health surveys provide the data needed for long-term projections, trend analysis, comprehensive evaluation of the health of the population, evaluation of needs and demands for medical care, and so on. Health surveys, if carefully planned, may be of great use in any country regardless of its level of development.

National practices in this field vary considerably. No standardized technique for the evaluation of national health surveys exists. International co-operation under guidance from the WHO may help progress in this field.

12.3. WHO activities in the development of methodology for health surveys

A number of WHO meetings and conferences have dealt with health survey methodology. For instance, in 1970 a WHO Expert Committee on Health Statistics (World Health Organization

1971) stated that many statistical indicators for the planning and evaluation of public health programmes may be established from the results of national health surveys.

In 1971, the Third European Conference on Health Statistics (World Health Organization 1972*a*) convened by the WHO Regional Office for Europe, discussed the comparative advantages of two main approaches in collecting data: surveys of medical records and health surveys by interview. In general it was noticeable that medical records have been used as a basis for surveys of morbidity and the utilization of medical care mainly in countries with integrated health services, presumably because standardization of recording methods is easier to achieve in that situation. In all surveys based on medical records, the greatest problems appear to lie in the standardization of the techniques of history taking, examination, and diagnosis. Such problems are much greater than those of sampling. The conference considered that interview surveys were a very valuable part of any health information system and that their importance was increasing. Their use in assessing recent health demography patterns and fostering public education in health matters was emphasized, since knowledge of public attitudes towards such matters can help in planning strategies.

The conference laid great stress on the value of interview surveys in the developing countries with their relatively scarce resources. In these countries routine statistics are either not available or relatively crude, and an interview survey may be the only source of information on health and the utilization of health services.

Another WHO Expert Committee on Health Statistics (World Health Organization 1972*b*) dealing with statistical principles in public health field studies, noted that sample surveys may be of special value in estimating both the needs for medical care and the health resources available to meet them. Surveys carried out on representative samples have a potential that has not been sufficiently exploited. In all such surveys, measurement techniques are fundamental. However, while the use of standardized procedures of clinical assessment is now widely accepted as essential in surveys of disease frequency, it has proved more difficult to find a uniform procedure to assess opinions and attitudes to new public health programmes. A standard measurement for social conditions and cultural background is also urgently required for aetiological studies of the relation of disease to environment.

A large part of WHO activities is directed towards the development of, and exchange of, information on new achievements in health statistics methodology. For example, in connexion with sampling techniques, work has been done on:

(i) use of adjusted ratios;
(ii) estimation in multi-stage sampling with unequal probabilities of selection;
(iii) further stratification introduced after selection of the sample;
(iv) determination of the optimum length of time during which respondents remain in a sample;
(v) replacement policy;
(vi) techniques of revising a sample when selection probabilities or sampling fractions within the strata need to be updated.

The participants of a WHO seminar on sample survey methods, organized in New Delhi in 1973 by the Regional Office for South-East Asia, felt that statistics collected routinely in the countries of this Region from the established sources such as civil registration, notification of quarantinable diseases, and hospital records are unreliable for the purpose of health planning, and that for an economic and timely collection of reliable data the sample survey technique should be applied. The development, by WHO, of sampling methods in health surveys would increase the value of assistance to countries. A specific manual on this subject concentrating on the potential of health surveys, on indicating the circumstances in which they are useful and methods of organizing them, rather than on sample design, sampling error and so on, would be of considerable value.

12.4. Surveys of infant mortality and fertility conducted with WHO assistance

Ad hoc surveys of infant and early childhood mortality, and fertility patterns

It has been demonstrated by a number of studies that mortality in infancy and early childhood is a major contribution to the high death rates observed in many areas of the developing world. One of the main objectives of both national and international health programmes in these areas is the reduction of mortality rates among children under five years of age.

Two recent programmes of the WHO Regional Office for the Americas made a significant contribution to a better understanding of health problems, especially in infancy and early childhood. The 'Inter-American investigation of mortality', carried out from 1962 to 1967 (Puffer and Griffith 1967), and in a sense continued as the 'Inter-American investigation in childhood' started in 1966, drew conclusions on analytical issues and made a practical set of recommendations. In both instances, the coordinated health surveys covering the whole of the Americas clearly demonstrated the value of collaborative efforts in studies of mortality and morbidity.

The current programme on infant mortality and fertility patterns is the first major inter-regional undertaking of the WHO in this field. The basic objectives of these *ad hoc* surveys are to provide scientifically sound estimates of levels and patterns of fertility, and mortality in infancy and early childhood and to give meaningful information on factors determining these levels and patterns. Five countries, Afghanistan, Algeria, Sierra Leone, Sudan, and Trinidad and Tobago, have agreed to participate in the survey programme: they present a wide range of social and economic conditions and are at various stages in the development of health services. Participating countries provide substantial financial and personnel resources for these projects, while WHO, with the financial support of the United Nations Fund for Population Activities, provides technical expertise and material resources for the planning and implementation of the programmes. The WHO project collaborators and their national counterparts meet periodically to discuss the progress made in the five-country projects and the problems encountered.

International comparative study of social and biological factors affecting infant mortality

This project forms a part of the coordinated programme of the WHO to promote the collection, appraisal, analysis and utilization of statistical information on health trends and differentials (World Health Organization 1973*a* and 1974). There would be many advantages, both national and international, in providing standardized basic statistical material. It was with this objective in mind that WHO set up, in 1972, a coordinated international investigation into the biological and social effects on perinatal mortality as the first phase in a long-term programme (Butler 1972). The present study extends the sphere of interest to the whole span of mortality in the first year of life, and is designed to promote the appraisal of the quality of data collected as well as their utilization for the planning and evaluation of child health programming in countries where infant mortality—though showing spectacular decline—still takes a prominent place in health policy considerations.

12.5. Health surveys in health planning—WHO assisted projects on health planning

Prior to an evaluation of long-term plans in the development of health services, a broadly-based survey of the current situation would be required to provide detailed and up-to-date background statistical material. Information on health personnel, and their training, institutional facilities, and current health programmes are vital, but the health planner should also know the state of health of the community and this involves the consideration of health indicators—socio-economic and demographic, morbidity and mortality.

The sources of knowledge lie in the analysis of vital statistics, in epidemiological information, and in special health surveys. The main task of a health survey group would thus be to gather the widely dispersed information, to analyse it and, in addition to routine sources, to supplement it by further specific surveys or studies.

The extent to which specific statistical information is necessary for health planning may be illustrated by the programme suggested for just such a broad health survey in Thailand (Llanos 1972), and similar to the requirements in health surveys undertaken in Colombia (Paredes-Manrique and Agualimpia 1972), Sri Lanka, and other countries. The WHO recommended, that in addition to the data available on a regular basis, a more detailed list of variables, which would be obtained in the main from special surveys, should be drawn up as described below.

General objectives

(i) To assess the present level of health.
(ii) To find the relationship between national health problems and certain demographic variables.
(iii) To determine priorities in the disease pattern according to morbidity, mortality and related characteristics.

Specific objectives

(i) To measure the trend of mortality or the morbidity pattern according to some defined variables.
(ii) To relate certain characteristics of the population to their impact on health.
(iii) To identify the leading causes of death or the leading causes of sickness according to some demographic variables.

Information required

Demographic variables. A wide range of data is required and ideally it should cover the past 20 years.

(i) Population according to age, sex, marital status, ethnic group, occupation, income, geographical distribution, level of education.
(ii) Population growth, and projection for the next 30-40 years by age, sex, and geographical distribution.
(iii) Fertility pattern (including number of live births, number of stillbirths, number of abortions, number of living children), according to the above population characteristics and parity.
(iv) Life expectancy by age, sex, and geographical distribution.

Mortality. Again, data should cover the last 20 years.

(i) Mortality rates according to above population characteristics, cause of death, medical care received and seasonal variation.
(ii) A special survey should also be undertaken to assess the quality of medical certification of death according to the same variables.

Morbidity. Data, ideally for the last 20 years, should cover in-patient and out-patient diagnosis according to age, sex, marital status, ethnic group, occupation, income, geographical distribution, educational level, length of stay, seasonal variations, average cost for each patient, and procedures carried out.

These data are especially important for selected diseases such as malaria and cholera.

Demand for medical care. A sample survey should be carried out to measure potential demand for medical care according to in-patient and out-patient diagnosis.

Details of the programme may be changed, according to local needs; however, a common core set of information is maintained in the majority of WHO-assisted projects on health surveys.

12.6. National health surveys and recent developments in this field

There is no standard methodology recommended for national health surveys, and the available working material is not explicit as to the methods used for sample design, data collection, quality control, interpretation, and so on. Because of such incompleteness, the review given in section 12.7 may be somewhat fragmentary and much effort is needed in future health surveys to improve outputs on the methodological side. Despite these shortcomings, some common approaches in health surveys might be discussed during this Workshop Conference with reference to population health, evaluation of health services, or study of medical care needs.

12.7. Recommendations and some problems for discussion

It is recommended that a central national organization assume responsibility for the national co-ordination of sample surveys in morbidity or other health problems. This responsibility might include: dissemination of general information about past, recent and current surveys; the co-ordination of information derived from past survey evaluation; and training of personnel.

Much attention should be given to the planning and evaluation of the whole national health statistics information system in accordance with needs for information as felt by health planners, health administrators or health managers. Health surveys would be of great importance within the system as a permanent source of information allowing a more detailed analysis of basic statistical data.

12.8. Review of some national health surveys

Local health studies and surveys

Comprehensive multi-purpose statistical studies in one place, such as a town or village which is typical of the whole country or a large region, have often been used as an indicator to measure long-term trends in population health, and to collect information in a degree of detail that can never be obtained by national or regional health surveys.

Nationwide health surveys

Australia. A national morbidity survey was carried out between 1 February 1962 and 31 January 1963, the results were published in 1969. In designing the survey, much attention was given to previous studies on morbidity statistics from general practice such as the National Survey of Morbidity in General Practice carried out in England and Wales in 1955/56 (Logan and Cushion 1958); the Washington Sickness Survey, 1953; an analytical study of North Carolina general practice, 1953/54; Canadian Sickness Survey, 1950/51; and small surveys carried out in New Zealand and Australia.

Morbidity data were needed to complement the well established and comparatively accurate mortality statistics, as much of the illness suffered in the community does not lead to death. Data were collected on disease frequency, severity, resulting incapacity, treatment, and so on; and it was hoped that the information produced would be of use in a broad spectrum of health administration and research such as:

Control of communicable diseases
Planning of preventive services
Study of social factors in morbidity
Study of genetic factors in illness
Planning of curative services

Estimation of the economic importance of morbidity
Research into aetiology and pathogenesis
Research into efficacy of preventive and therapeutic measures
National and international comparative studies of diseases, accidents and impairments
Planning of undergraduate and postgraduate teaching curricula
Guidelines for the planning, production, and research of pharmaceuticals

Such a list of objectives for the use of survey information might be of assistance in the planning of other surveys since the use or non-use of information has become a problem, which requires for its solution better cooperation between health administrators and health statisticians.

Within the three stages of the Australian pilot survey, various recording systems were examined in detail and it was finally decided that each record card completed by the participants would cover one episode of illness. This was defined as 'any departure from the person's usual health which led to a consultation with a medical practitioner'. The survey was confined to those episodes of illness for which the patient was seen at the doctor's surgery, in the person's home, or at the scene of an accident, but to avoid duplication, did not include those seen at a hospital as these would be covered in hospital morbidity studies.

The patients seen by the survey participants totalled 1.61 per cent of the Australian population (1.19 per cent of the metropolitan and 2.14 per cent of the non-metropolitan population), as compared with the 0.86 per cent of the population in the England and Wales survey. In view of this large coverage, a fair amount of reliance can be attributed to the results.

Analysis of the results shows that:

(i) 172 078 persons were attended by 85 doctors in 79 practices during the survey year;
(ii) 258 578 illness were diagnosed;
(iii) 49 193 non-illness† episodes were recorded;
(iv) 559 014 attendances were made by patients relating to the 275 032 episodes commencing during the survey (3.25 attendances per patient; 2.04 attendances per episode);
(v) there were 1.72 illnesses and non-illness† episodes per consultation.

General practitioners have been mainly concerned with treatment of respiratory diseases–19 per cent of all illness episodes; accidents, poisoning and violence–11 per cent; skin disease–7.6 per cent; digestive diseases–7.1 per cent; diseases of nervous system and sense organs–7.0 per cent, and circulatory system diseases–5.0 per cent; non-illness symptoms and senility represent 21.1 per cent of all illness episodes. These categories constitute 77.8 per cent of the main causes of illness episodes, and 77.2 per cent of attendances were in connexion with them.

A more detailed analysis showed a breakdown by classification of disease, chronicity, age, sex, seasonal occurrence, occupation, geographical distribution, incapacity, attendance rate, and some comparative characteristics related to the UK and USA studies.

Colombia. A study on human resources for health and medical evaluation was carried out from 1964 to 1967; the final publication appeared towards the end of 1972 (Paredes-Manrique and Agualimpia 1972). The following sub-systems of the study were identified:

(i) the national morbidity investigation;
(ii) medical manpower;

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† The non-illness episodes included such things as insurance and other examinations, immunization courses, ante-natal examinations, normal delivery and post-natal care, contacts with infectious diseases, skin sensitivity tests, and persons without specific complaint or sickness symptoms.

(iii) nursing manpower;
(iv) institutions providing medical care;
(v) medical and nursing education.

A specific methodology was designed for each study area to meet its scope and aims, and the overall purposes of the study. Because of the importance of morbidity as an indicator of the country's health needs, it was decided to conduct a national study, which, besides determining the incidence and prevalence of illness, would be concerned with such matters as the environmental background, socio-economic correlation, and the development of disability indices. The study was designed also to measure the coverage of medical, dental and hospital services.

The morbidity study employed a probability sample of the Colombian population. It included two defined phases.

(i) Household interviews provided information about the background history of illness and medical care. These interviews, each lasting about half an hour, were conducted by medical students under the supervision of public health physicians.

(ii) A sub-sample of the people interviewed received physical examinations. These gave valuable information as to the percentage of illness and identification of illness independent of the patient's awareness.

The probability sample used provided a mathematical basis to estimate the parameters within specific confidence limits. The sample was selected in two stages. First, the primary sampling units were defined (a village or cluster of villages with a population of over 5 000), and grouped into 40 strata representing different characteristics; one unit was randomly chosen by controlled selection from each stratum. Secondly, 24 segments, each of about 10 dwellings, were drawn from each of the 40 selected primary sampling units. The final sample included 8 920 households comprising 52 479 individuals, 98.1 per cent of which were actually interviewed.

A sub-sample comprising about 10 per cent of the individuals included in the household interview was selected for physical examination. Of the 5 258 individuals chosen in this sub-sample, 5 026 received physical examinations; a coverage of 95.6 per cent of those selected.

A similar sampling approach was used to choose the doctors for the study of medical manpower; they were interviewed in investigation hospitals and health posts. Information on graduate nurses was obtained from mailed questionnaires.

The results from these surveys established a number of indicators for the estimation of the population's health; and it provided the impetus for the initiation of health planning, from which a policy has been gradually taking shape. To carry out this general health policy a national ten-year plan has established guidelines and targets for health activities throughout the country; defining both national goals and those value judgements necessary to formulate a national plan composed of separate health plans for every region, together with recommendations for arranging priorities and making the best use of a budget.

The results of the integrated study were also used to control specific health problems; as a basis for the re-organization of the health services; in manpower planning; in developing research programmes; and in better orientation of medical education.

Finland. A study on utilization of medical services and its relationship to morbidity, health resources and social factors, was carried out between 1964 and 1968. The objective of the study was to describe the quantitative level of utilization of the medical services in various parts of the country and in various groups of the Finnish population prior to the implementation of a general sickness insurance scheme (Purola, Kalimo, Sievers, and Nyman 1968). Attention was paid to the sickness expenditure of the families, and the study also attempted to elucidate the effects of the social conditions of the population upon the utilization of the medical services. Hence, data were collected on family income level, distance from medical services, and availability of medical services. These factors were selected as a descriptive framework because it was assumed that the relationship between the need for medical care and utilization of the medical services was less defined the lower the family income, the remoter the family dwelling from the suppliers of medical services, and the less adequate the medical services available in the commune of domicile.

The fact that the community administration of health care is organized in regions made an ecological examination a suitable method of describing the supply of medical services. An analysis of this type showed not only how well regionalization had succeeded in producing an equal supply in different regions, but also allowed the examination of the relationship between supply of medical services and other regional characteristics. Particular attention has been paid to the differences between urban and rural areas, for urbanism may be regarded as the most important factor characterizing regional differences.

The material was gathered by family interviews using a questionnaire comprising 109 questions, mostly with closed answers. Questions dealt with utilization of the medical services, sickness, family income, expenses of utilization of the medical services, degree of remoteness of family dwelling.

Attempts were made to interview a sample representative of the entire non-institutionalized population of Finland. The preliminary sample of the study consisted of 7 190 persons (one-fourth of the 1963 sample of current labour-force study carried out by the Ministry of Communications and Public Works). A total of 6 387 interviews took place covering 23 517 persons (16 715 adult family members and 6 801 children). Of the interviews planned, about 9 per cent could not be carried out: the non-response rate was particularly high in the city of Helsinki (27 per cent) and the borough of Espoo (21 per cent). There were 1 959 interviewers, mainly public health nurses or community midwives, and most had experience of interview work from previous surveys.

The three-week interview period was from May 19 to June 8 1964. Most questions dealt with events between the first day of the year and the interview day. Hence the average length of the study period was about 5 months. The length of interview depended chiefly upon the number of family members and their sicknesses. On average the interviewing of one family took 58 minutes.

The coding of replies was split into two processes: diagnoses of diseases were coded in one process; then the replies to the whole questionnaire were coded as an entity. This made it possible to check the compatibility of replies, and 0.5 per cent of the questionnaires returned were discarded because of contradictions or omitted replies. For statistical processing by computer the data were transferred from punched cards to magnetic tape. Certain checks against punch-card errors were made concurrently. The data of the sample were checked against the statistical data on the entire population of the country (available from the official statistics) and it was thus possible to examine the representativeness of the interviewed sample by family and by individual. In this comparison, more attention was paid to the sizes of the differences between sample and population than to their statistical significance. With such a large sample, the standard errors were very small and even slight absolute differences were usually significant, but this did not lessen the validity of the data.

Among the most important factors influencing the sickness behaviour of people and their use of medical services were the state of health perceived by them and the disability suffered. Data were collected on the following variables describing disability (i) and morbidity (ii-v):

(i) number of restricted activity days and days of confinement to bed;

(ii) sicknesses causing confinement to bed;
(iii) sicknesses giving rise to the latest consultation with a physician;
(iv) prevalence of chronic conditions;
(v) prevalence of ailment for which the respondents required medical treatment, which had not been included in the other questions regarding morbidity.

The size of the sample (16 715 adults) meant that it was possible to aggregate the individuals' need for medical care, to give measures of need for various groups in the population, and by age/sex distribution. These results would then be compared to the distribution of prevalence of illness using categories (ii) to (v) listed above. These results supported certain conclusions concerning the validity of the technique of estimating the need for care from interview data.

Reviewing the findings of the study, the Finnish experts considered that national health surveys are an essential and accepted part of medical information. The interview method was regarded as being the best method whenever information is desired about the number of days of bed confinement and acute mild sicknesses or injuries that do not give rise to a visit to a physician, or regarding phenomena consequent upon sickness such as absence from work or school. The interview method has been applicable also in surveys of the relationship between the use of the medical services and demographic, social and economic factors. The interview method may further be the best way of measuring what the individual perceives his state of health to be. Comparison of morbidity data obtained by interview with data obtained from physicians or from hospital sickness reports produces results of greater conformity than do comparisons with the sources of general health examination.

Japan. Since 1953 a National Health Survey has been carried out on a certain date in May every year, in order to collect general basic data concerning the characteristics of sample areas and the living status of a sufficient sample of households, and the members of the households (Soda and Kosaki 1975). These are needed for the planning, management and evaluation of health and welfare administration and the surveys can concentrate on collecting information of special health interest, together with related items such as socio-economic status of the household, including family income or expenditure, main occupation and industry, and so on. At the same time, this survey, which was made on a large sample of areas, provided the sampling frame for a number of small-scale area surveys which were to be carried out by the Ministry of Health and Welfare in the same fiscal year. In the basic survey for the Health and Welfare Administration in 1970 for instance, 1 815 census enumeration districts (out of a total of 480 642 districts at the 1965 census) were selected on a statistical sample scheme, and the survey was made on all households and their members in the selected sample areas.

The National Nutrition Survey was initiated at the end of the Second World War to assess (i) the total amount of food stuffs of various kinds consumed by the Japanese people as a whole, and (ii) their nutritional status by the measurement of stature and body weight, and medical examinations to discover nutritional deficiency, enabling the government to estimate the necessary amount of food stuff to be produced or imported. For the purpose of improving the accuracy and representativeness of data the selection of sample areas for the survey has been made on a random sampling scheme since 1952. The survey is still continuing and furnishes a considerable amount of data—on food consumption which affects the prevalence of adult diseases; on the growth of children; and on the health status of the Japanese nation as a whole—by sex and age, locality (urban and rural), social and economic status.

A number of special statistical studies on the epidemiological features of various diseases were carried out jointly by the Health and Welfare Statistics Department and other Bureaux in the Ministry of Health. The data in these studies were obtained mainly by medical examination of certain age groups in selected sample areas. These data were supplemented by information obtained from interviews. These surveys were repeated periodically, every five years for the tuberculosis and every ten years for the adult diseases for example. For control purposes, some people underwent a follow-up examination two years later. Similar surveys, with some modifications, were carried out on mental disorders, physical impairments, dental health, physical development of children, chronic diseases of children and other topics.

Highly reliable statistics on the number of patients who visited medical care institutions are also continuously collected by the enumeration of in-patient and out-patient consultations and treatment in a number of hospitals and clinics selected on a statistical sampling basis from the National Register of Hospitals and the rosters of medical and dental clinics. This 'patient survey' gives further information on the number of patients by types of diseases and injury, types of medical institutions providing medical care for them, and the ways of paying the cost of services such as by health insurance of several kinds, by the Daily Life Assistance Scheme, or by the patients themselves.

To advise the Ministry of Health in carrying out the above undertakings, a group of mathematical statisticians were invited to organize the Sub-committee on Statistical Methodology in the Health and Welfare Statistics Council. One of the most important contributions of this sub-committee was the proposal to prepare a large master sample, from which various smaller sample surveys could draw their samples, together with the basic information on individual characteristics.

Sri Lanka. Advantage was taken of a socio-economic survey to include items on morbidity and fertility. The survey was conducted on a sample basis and covered 12 000 households (World Health Organization 1973*b*). During 1969-1970 there were four rounds each covering 3 000 households. Some items of inquiry on morbidity were included in the questionnaire which was drawn up in consultation with epidemiologists. The results (listed below) are available on a regional basis by sector (urban, rural, estate), and for the whole island:

(i) ill persons in sample population by age and sex (five-year groups);
(ii) period of absence from normal duties by age and sex (15 years upwards);
(iii) source of treatment by districts;
(iv) illness by place of treatment–indoor/outdoor;
(v) illness by household size;
(vi) illness by occupation or income;
(vii) illness by ethnic group;
(viii) cause of illness by age group.

Various questions on fertility were also included in the questionnaire because of its importance in relation to health standards and economic development. The questions were designed to supplement the various fertility indices that can be obtained from routine resources.

USSR. In connexion with the All-Union Population Census of 1970 there was a combined sample survey of the health of the population (World Health Organization 1973*b*). The purpose of the survey was to obtain a complete picture of the health of the population by studying morbidity, population movement, physical development and the relationship between health indices and environmental conditions. Typical areas were selected on the basis of an analysis of current statistical data on infant mortality, morbidity, hospitalization, the doctor/population and hospital bed/population ratios, the distribution of industry and other economic and geographical features of the country's various regions. Altogether, the sample for the morbidity survey comprised 4 per cent of the urban population and 1 per cent of the rural population.

In order to study the influence of the availability and accessibility of specialized medical care on morbidity indices, and to obtain more representative material, the work was carried out separately in large, medium and small towns and in small rural centres. The minimum programme for the combined study, which was mandatory for all the selected centres, included: a survey of morbidity based on figures relating to applications for medical attendance during the period 1969-1971; a study of vital events based on the records of local statistical offices; and an environmental health survey based on information from sanitation and epidemiological centres and from public health authorities.

To assess more accurately the prevalence of chronic diseases and to reduce the size of the population sample, use was made of the applications for medical attendance during the 3-year period 1969-1971, with a subsequent check of the completeness of these case-findings through direct medical examination of part of the population. Medical examinations were carried out in 1970 and 1971 in a smaller number of localities. There were also arrangements for the persons undergoing medical examination to be interviewed to determine the relationship between their health status and environmental conditions.

The more complex sections of the programme relating to the epidemiology of prevalent diseases, study of the causes of death, occupational mortality, physical development, and the relationship between the health and living conditions, were dealt with by medical research institutes as part of their planned programmes.

The results of experimental work showed that a considerable proportion of those suffering from chronic ailments do not seek medical advice every year. Hence, one-year attendance statistics are not sufficient for a study of the prevalence of disease, and this was one of the reasons why a three-year observation period was introduced. Based on applications for medical attendance over a three-year period, a fairly accurate estimate can be made of the number of persons involved and an average annual morbidity rate estimated from the observations.

Longitudinal surveys following a more complex programme were continued with a morbidity study of industrial workers incapacitated for work. These investigations included analysis of living and working conditions in the main sectors of industry. The trends established have enabled a number of measures to be recommended for the protection of health of industrial workers.

A number of medical research institutes have initiated epidemiological studies. A successful analysis was made of screening data relating to people of the age group 80 and over. In the course of the examination, data was collected by the Institute of Gerontology on morbidity, living conditions and medical care for the group concerned. The Institute of Cardiology collected data on hypertension and coronary heart disease in different demographic, professional and ecological conditions. Seventy-five towns were selected for examination of a representative population sample by standardized methods. Similar surveys have been organized by the Institute of Haematology (leukaemia), Institute of Neurology (cerebro-vascular disease), Institute of Oncology (neoplasms), Institute of Nutrition (obesity) and by the Institute of Psychiatry (schizophrenia).

Such multi-purpose studies with a five-to-ten year interval between them have been considered as an important supplementary source of health information needed for long-term planning and evaluation of health programmes. However, to meet these requirements efficiently, the statistical methodology used in such complicated health studies has to be more elaborate in terms of optimal application of random sampling and typological stratifications which could be of much value in saving resources and increasing the representativeness of samples.

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Paper 13

Methods in the US National Health Interview Survey

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13.1. Summary

This paper describes the beginnings of health surveys in the USA, and the organization of the US National Health Interview Survey. It describes the considerations which influenced the contents of the survey; the methodology of core questions, and supplementary sections which can be added into the questionnaire on a rotational or an *ad hoc* basis, with the possibility of follow-up surveys on special topics; and the length of the interview. It also covers the problems of defining concepts and standardizing the meanings of the questions so as to ensure unambiguous returns; the uses of pretests for questionnaires; and the training of interviewers. It discusses the advantages of continuous surveys, and comments in detail on the weaknesses and strengths of interview surveys.

13.2. Introduction

Health interview surveys in the USA date back to 1920, when a study was conducted to assess the health and nutritional status of people in the cotton mill villages in the south-eastern part of the country. This was followed by other health surveys in a few scattered cities until, in 1935, a major general purpose interview survey was launched in 700 000 households in 83 urban places across the nation. Although the results of this major effort lacked the precision of today's survey and sampling techniques, these results were quoted and used during the following 20 years. Between 1935 and 1956 there had been so many major changes in the structure of the population, methods of medical treatment, and the delivery and financing of medical care, that the results of earlier studies could no longer be used to fill the needs for health data. These needs were expressed by legislators, educators, demographers, research workers, planners of health care programmes, and the private suppliers of health services and products. In 1956 legislation was passed for the operation of continuous health surveys and special studies. The National Household Interview Survey has been collecting data continuously since 1957.

For most of the time since its inception the interview survey has included about 42 000 households or 130 000 people each year. It is based upon a national probability sample which excludes only the population living on military bases and those in residential institutions. The sample is designed to provide data for the nation, for four major geographic regions, and for the 31 largest metropolitan areas, but not for individual states or counties. Each year a new sample is drawn. The annual sample is divided into 52 sub-samples, each of which is representative of the national population.

Interviews are conducted on one sub-sample during each week. With this design data can be accumulated over any period of time and annual estimates can be produced which are free of seasonal bias.

13.3. Planning the survey

During the initial planning of the survey some very difficult decisions had to be made. Approximately 400 individual experts and organizations in the health care field were asked what they thought the survey should produce, which resulted in a long list of items, topics, and methods. It was in no way possible to collect all of this information within the limits of staff and money available, and the hardest task was to decide what not to attempt at the outset. Among the sacrifices were:

(i) A design that would permit collection of representative data for individual counties and states.
(ii) Longitudinal or repetitive data on the same individual over a period of time.
(iii) Complete tabulations and analyses of the interrelationships among diseases and medical care within the family unit.
(iv) Subjects that might be personally sensitive and thought to be an invasion of privacy.
(v) Health topics of interest to a very limited number of users, perhaps for a marketing purpose or to test some hypothesis, as differentiated from topics of general interest to the health care professions.

Even with these restrictions it was impossible to include, during a given year, all of the subjects in which there was an interest, and therefore resources had to be spread through time to meet the heavy demands. To do this, a basic core of items was established which are included continuously on the questionnaire; other topics are scheduled to rotate on and off the questionnaire at intervals of three to five years; and still other supplemental topics of timely interest are included on a once only basis.

The basic core includes demographic items such as geographical location, age, sex, family size, income, education, marital status, and employment, according to standard definitions used by the Bureau of the Census. In addition, the continuous items cover acute illnesses, injuries, work loss, school loss, days bedridden, chronic limitations of activity, physician and dental visits, and hospitalization. These items are mentioned simply to indicate the range of population characteristics to which the additional rotating and supplementary topics may be related. The rotating topics included at intervals have included use of prescription medicines, smoking habits, limitations of mobility, and personal health expenditures. *Ad hoc* or supplementary topics could be, for example, provisions for health care in the home, use of medical X-rays, use of specialist services, length of convalescence after hospitalization or surgery, and the impact of specific chronic diseases.

In addition to this framework of the questionnaire, there has from time to time been a 'second-stage' survey. During the original interview a few questions are asked which identify a particular group of people, for example, those who have hearing impairments. The interviewer then leaves a separate questionnaire to be completed by the identified person and to be collected or mailed-in at a later date. A variant, rather than leaving a questionnaire, is to screen the original answers at the central office. For all, or a sample, of the identified sub-population a second interview or mailed questionnaire is then used to obtain details; for example, medical care for the hearing problem, time of onset, use of and satisfaction with hearing aids, special training, and the like. Such second-stage survey data can then be linked to the initial interview data concerning the same person. This device is useful where certain household records need to be checked. But the principal advantage is in securing detailed information on additional topics without increasing the length of the original interview and thereby causing fatigue in the respondent and loss of data quality.

It is usual in the household survey to limit interviews to a range of 30 to 80 minutes. In addition, the health questions are taken early in the interview, while the interviewer and respondent are fresh, and the more routine household demographic questions reserved until the end. This seems to produce more complete responses on the health information without seriously affecting the demographic data. The problem of interviewer and respondent fatigue and the length of the interview are mentioned because there are always strong pressures to overload a questionnaire on a single visit interview. One commonly hears the statement 'As long as the interviewer is at the house it will be easy and inexpensive to ask a few questions on my subject'. Yet a few more questions on each of a number of topics can rapidly increase the interviewer-training requirements, the length of the interview, data-processing time and costs, and the complexities and costs of the analysis and report stages. A common result of overloading an interview is that within a fixed budget and staff allocation, too high a proportion becomes used up in collection and processing, leaving far too little for analysis and production of the end results. The entire survey process is slowed down and users who at the outset were enthusiastic about receiving the data become disgruntled when told it will be a year late. Those officials who have responsibility for decisions on priority of content must also be aware of how their decisions will affect the staffing, costs, operation, quality, and timeliness of the survey.

13.4. Designing the survey

In designing a health interview survey, one of the most important considerations is to determine what the user wants to know and then to set down in precise terms the questions that must be asked. On the surface this sounds easy, but experience shows that this is one of the most difficult of all tasks. Often the user cannot state clearly what it is he wants to know; sometimes what he wants to know cannot be reliably obtained by interview techniques. If it *can* be obtained by interview, the questions must be understandable and have the same meaning to all classes of the population, so that the answers will be clear, precise, correct, and without ambiguity. This first step takes a great deal of time and testing, but it is worth the effort. The ultimate data are no better than the individual responses, and there is nothing more frustrating than to discard a body of data because the answers were unreliable. Closely related to the above is the need for precise definitions, set forth on paper, so that the meaning, and inclusions and exclusions will be known to the interviewer and respondent, and later to the analyst who must interpret and report upon the findings. Virtually every item of information requested or recorded requires a definition. In survey work standard definitions should be employed wherever those definitions do not alter the intended uses of the data. One of the current efforts in the USA is to try to obtain agreement among federal and state agencies on minimum basic data sets along with standard definitions for various classes of health statistics. This is a slow process, but it is hoped that it will ultimately lead to greater comparability of statistical information.

The design and format of questionnaires also require a few words. As the number of subjects or topics increases, questionnaires become more complex. They must be designed for easy use by the interviewer and yet in such a way that questions are not asked about household members to whom the questions obviously would not apply. On a few occasions a set of items has been placed in a location on the questionnaire where they have been missed. If such errors occur, one must accept a high item non-response, or else go to a costly procedure of call-backs to obtain the missing items, or change and reprint the questionnaires. Whenever a new survey is started or an old one revised, two or three pretests are always run. The primary purpose is to determine whether the questions are worded properly, whether there are definitional problems with inclusion or exclusion of certain characteristics or events, and whether the questionnaire is well designed for completeness of entries and for ease of use during interviewing and data processing. However, a good pretest may also provide other valuable information, some of which is listed below without detailed comment.

(i) Whether the interview is too long or too complex. Does the interviewer have trouble managing it, or does the respondent become confused? Are there topics that should be dropped?

(ii) Whether the planned field operations will proceed smoothly. Is the flow of questionnaires from interviewer to supervisor to data processing efficient?

(iii) Whether the code classifications planned are the best ones in view of the frequency of response to the questions. For example, on an item which has five code categories, are 90 per cent of the cases falling into a single category? Should the codes be changed or should the questionnaire be changed?

(iv) Whether frequency of responses to an item or topic will support the degree of detail planned in tabulation. Judging from the pretest, will the final sample have enough cases in it to warrant cross-classifying a certain item by age, sex, and income? Should the tabulation plans be altered?

(v) Whether the full-scale survey can be done within the limits of staff and budget provided for it. What is the unit time and cost of an interview? Of processing a record? In view of these estimates, will there be sufficient funds for analysis? Must consideration be given to reducing the content or sample size, or extending the time of the survey?

Certainly not all questions can be answered by pretesting, nor perhaps even some of those posed above, but pretests, built into the survey plans, can pay for themselves by avoiding pitfalls in future work.

Small groups of interviewers receive training prior to pretests but major training sessions, lasting two days for experienced interviewers, are conducted before each full-scale survey. This training covers interviewing techniques, concepts, definitions, sequence of questions, how to handle problems; and also administrative matters, such as making call-backs, transmitting questionnaires, and that all-important matter of records needed in order to get paid. Usually at the end of regular training sessions each interviewer is assigned a few household addresses in which to conduct practice interviews. Upon completion of these, the interviewers and any observers reassemble to discuss and resolve problems they may have encountered. Newly employed interviewers receive a full week of training and practice interviews, together with tests of proficiency. One of the first two assignments [8 households] on a new questionnaire, or the first two assignments of a new interviewer, are observed by a senior interviewer or supervisor. Thereafter, at least one assignment for each interviewer is observed every calendar quarter.

13.5. Survey continuity

It is evident that a feature of the household survey in the USA that distinguishes it from most others is its continuity. First, the interviewing takes place week after week for the entire year and, secondly, there is continuity from year to year. These features offer many advantages; some of them have been suggested earlier, but for clarity they are enumerated here.

(i) A continuous survey enables the organization to function with a stable staff of moderate size, and with a variety of skills. This discourages the job hunting or job changes that of often take place with *ad hoc* surveys as each phase–planning, field work, processing, and analysis–nears completion.

(ii) The staff builds experience with time. Planning and designing operations mentioned earlier are accomplished more smoothly on successive changes in the questionnaire. Even with the interviewers, there is a good deal of transference of skills from subject to subject. Studies conducted on the US survey indicate that on average the interviewers reach their optimum performance after 18 months of experience. About 75 per cent of interviewers have been with us for two years or longer. Similarly, a stable staff of 12 experienced clerks edit and code the questionnaires as they arrive in weekly batches.

(iii) Sources of errors can be detected early in the survey year in time to make corrections in the interviewing or coding processes. During the first four weeks of a new or revised survey, the questionnaires are subjected to a 100 per cent field edit. Throughout the year a 10 per cent sample is also independently coded by a coder and two verifiers and a 3-way comparison is made on an item-by-item basis. In addition, during the initial 2-4 weeks, one of the statisticians who planned the survey content sits in the coding room to resolve coding problems and to detect any frequent recurrence of answers that are inconsistent with the initial concept or intent of the question. The combined process of intensive early editing, verification, and professional review makes it possible to modify interviewing and processing instructions before substantial damage has been done to the entire annual survey results.

(iv) It has already been mentioned that weekly interviewing throughout the year produces annual data free of the seasonal bias which might occur in a shorter survey. This is not so important in measurement of the prevalence of chronic conditions and long-term disability, but many kinds of acute illnesses and injuries have seasonal fluctuations or epidemic periods that would result in measurement bias if the data were assumed to be typical for any period other than that actually covered by the interview. The advantages of a continuing survey apply also to measurement of the use of medical care, which varies not only with the incidence of episodes of acute illness, but also with other factors such as vacation periods and holiday seasons.

(v) Measurement of characteristics or events of low frequency can be obtained with reduced sampling error by combining two or more years of data from a continuous survey. Even for events of higher frequency it is possible, by combining several years, to produce more detailed cross-classification among the demographic variables. The characteristics for which more than one year of data are being combined should be those which are fairly stable from year to year, such as the number of people who are confined to bed, or the number who have impairments of vision in a particular age and ethnic group.

Perhaps the greatest disadvantage, other than cost, to a survey that continues from year to year is that there are four stages of work going on at any one time: planning, collection, processing, and analysis. Unless adequate staff is provided to carry out and supervise each of these functions concurrently, the efforts of the professional staff may become focused to meet a crisis or priority situation in one stage, at the sacrifice of another stage. A related disadvantage is that there is a long time-lag between the planning and the results. In the US Health Interview Survey, planning and pretesting new topics starts at least 8 months before a new survey year. Most topics require accumulation of data from 52 small weekly sub-samples in order to produce estimates with an acceptable degree of sampling precision. It then requires another 4 to 6 months to do the final coding, editing, imputation, and weighting; and to produce tabulations. In all, it is at least two years from the time the information is requested until the initial results may be seen. This time lag is much too long for users who want data on some current health issue, particularly if they would be content with less precision than the survey is designed to produce. Planning, collection, and tabulations from a respectable *ad hoc* survey of the same size might be accomplished in a year, but on the other hand, the needs of many users would not be met at all if the continuous survey machinery were not available.

A few countries conduct surveys, or are planning to conduct them, by a method which combines some of the advantages of a continuous design with some of the flexibility of *ad hoc* surveys. This is done by the creation of a master population sample composed of a number of representative sub-samples. Depending upon the need, all or any number of the sub-samples may be used, or use of the sub-samples may be sequenced with respect to time. This permits *ad hoc*, repetitive, or even continuous surveys to be conducted. In principle, surveys of varying content are conducted throughout the year in such a way as to enable the operating organization to maintain a stable, experienced staff. In practice, there are usually severe peaks and valleys in the workload, depending upon the requirements of the sponsors.

13.6. Weaknesses of the interview survey

Interview surveys, whether they be *ad hoc* or continuous, have certain inherent weaknesses which the National Center for Health Statistics (NCHS) has struggled with for many years. One of these is a lack of completeness and diagnostic accuracy in the reporting of chronic diseases. Research on this subject has established that there are a number of reasons, principal among which is a lack of communication between the physician and patient, which make the patient unable to pass on a definitive diagnosis. Both completeness and accuracy are highly related to the impact which the disease is having on the respondent at the time of interview. Diseases which cause disability are well reported and for this reason disability by cause is regularly tabulated. The volume of reporting is also greatly increased if the survey concentrates on a particular disease, or diseases of a single body system, asking many probe questions about medications, medical services, work loss, past episodes, and so on. In the early years of the survey, data was collected on the prevalence of all chronic diseases, but now questions are asked about diseases of different systems over a 6-year rotation cycle. Of course an interviewer cannot obtain information which the respondent does not know, so undetected diseases are never reported. Such cases are discovered, however, for those diseases included in the Health Examination Survey, which is covered in paper 15.

Another frailty of household interviews is that information is often concealed if it is considered by the respondents to be an invasion of privacy, embarrassing, or a threat to their rights or benefits. For this reason there may be gross under-reporting of certain diseases and conditions, such as cancer, mental illness, urogenital diseases, alcoholism, and drug use or addiction. In the early years of the US surveys, questions on abortion, sterilization, or contraceptive practices would not have been considered, but such subjects have gained much more public acceptance in recent years. Questions concerning sources of income and benefits from welfare programmes must be carefully phrased to avoid suspicion by respondents that the information will somehow be used against their interests.

Interview surveys may be so designed that a person replies only for himself or herself; or they may be designed to accept answers from a responsible family member to questions about other family members. When proxy respondents are used, the data may be biased because the respondent sometimes does not have full knowledge about the health status, medical care, or other questions concerning other family members. Yet if each person must respond individually, the survey costs are multiplied or the number of sampled persons must be greatly reduced. In the household interview survey in the USA, adults respond for themselves when they are at home during the time of the interview; otherwise a responsible adult responds for children and for other adults, who are not at home but are members of the immediate family. The respondent rules result in about 60 per cent self-response. Methodological studies and pretests will often reveal that certain questions cannot be answered by proxy respondents and these can then be eliminated from the final questionnaire. Questions that must be answered by self-response, such as those relating to attitudes or to health services received at the place of work, may have to be answered through a separate supplementary questionnaire which is left at the household to be mailed-in or collected later. This method has been used with reasonable success for obtaining data on family medical expenses. By leaving a questionnaire the basic interview is shortened, the best respondent may be obtained, and opportunity is provided to check bills or receipts for purchases. Where a specific respondent has to supply additional information, telephone interviews have been used.

One of the decisions that must be made in planning a survey is the length of time over which respondents can accurately remember events, the so-called memory bias of respondents to the question. One would like to make the time as long as possible because more events—injuries, for example—are covered, and this reduces the sampling error of the estimate. However, if events are unreported because of memory bias, this may outweigh the sampling advantage of the greater number of cases. A considerable amount of research has been carried out on this complex subject, but there is still much to learn. For acute illnesses and injuries, a 2-week recall period is used; but questions cover only illnesses or injuries that caused the person to reduce activities for a day or more, or that required medical attention. This is partly because events that have higher impact on people are those which are best remembered. A 2-week recall period is also used for reporting visits to physicians and dentists. When annual estimates are required for all acute illnesses, injuries, or visits during the year, the two-week data are multiplied by 26. In a special supplement on visits for medical X-rays, a 3-month recall period was selected after time intervals which varied from two weeks to one year had been tested. Many years ago people were asked to report hospital in-patient episodes during a year and annual estimates were produced from these responses. The memory bias was about 10 per cent under-reporting. Again several studies were made of this problem. The questionnaire still covers episodes during the entire year, but on the basis of dates of hospitalization, episodes during the past 6 months are tabulated and the annual estimates of the number of hospital discharges are produced by doubling this. As a result memory bias has been reduced to about 4 per cent. However, the 12-month recall period is still used to estimate the number of people who have been hospitalized one, two, or more times during the year. Probably every question has its own optimum recall period, but having many different recall periods would be impractical and confusing to both interviewers and respondents. Although research on memory bias of different questions is very valuable, the design of the survey and the final questionnaire must be a compromise which takes into consideration the sample size, respondent rules, memory bias, length and complexity of the questionnaire, and the overall precision of the estimate expected by the user. Present knowledge of how to put these elements together in the best possible design is quite rudimentary, and therefore a great deal must be left to the judgment and experience of the survey planners.

Still another weakness that may exist in surveys is non-response bias as a result of missing people who are not at home or who refuse to answer the questions. The problem is that people who are not at home might have provided different answers from those who were interviewed. This has not been a great problem in the Health Interview Survey. After making an initial visit and three or four call-backs, the non-response rate is 5 per cent, including 15 per cent refusals. Nevertheless, data on certain topics within a questionnaire can be biased by non-response. For example, when length of recall for medical X-rays was studied there was a 22 percent non-response on the day of the interview when any member of a family was in a hospital. This means that in a household survey there is a non-response bias to questions on hospitalization, and that there is also a bias on subjects related to hospitalization, such as medical X-rays. The impact or severity of the bias on the data is reduced by using a longer recall period, which is one reason a 3-month recall, rather than 2 weeks, is used for medical X-rays.

Interview surveys are conducted on samples of the living population, and generally do not include questions about former or deceased members of the family. They are intended to measure the prevalence of conditions, and the experience in the immediate past of the current living population. The omission of dead people produces no bias in these estimates. However, persons who have died during a given period of time, say, one year, have had diseases and injuries, and have therefore added to the workload of physicians, other health workers, hospitals, and health agencies during that period of time. In the US Health Interview Survey, conducted continuously throughout the year, half of the people who died during the year are not included. This means that if the user of the results wants information about the total number of events to which dead people have been large contributors, the data will not be complete. The extent of incompleteness varies according to the topic of the questionnaire and, of course, is greater at older ages. Estimates have been made of the under-coverage of hospital data from surveys by making retrospective studies from death certificates. Data on hospitalization, or other events highly related to mortality, are better obtained from sources of records which include deaths, if they are available, rather than from survey methods.

Interviews cannot be expected to provide the kinds of technical details that are available from medical records, such as procedures performed, laboratory tests, or medications prescribed. On occasion in the past the interview survey has been used to identify individuals who have received a particular service, and permission to go to the physician or clinic or hospital for more detailed technical information about that service has been requested. This method combines the advantage of having the social and demographic information on a probability sample of the population linked with the information available from records about the same population.

13.7. Strengths of the interview survey

Although health interview surveys have a number of weaknesses, as indicated above, they also have strengths which have led the USA to maintain these surveys continuously for 18 years. A well-designed population sample permits the production of data estimates for the entire population and not just for a particular geographic area or for a specified sub-group. Most statistical studies that are made from records relate to a selected group of people, such as those who are eligible for a certain programme, those receiving care in specified types of facilities, or those who may be residents of institutions. A general population survey covers all the people and eliminates the need for hazardous generalizations from data on groups that may be atypical.

A related advantage of the interview survey is that the survey generates the denominator data—the population size and characteristics—at the same time that it generates the numerator data on health status, utilization of services, and related subjects. This makes possible the production of more accurate rates than may be produced from the records of health care institutions or programmes, which may depend upon limited denominator data from some independent outside source.

Most studies which are based upon record sources obtain information concerning separate episodes of care. Interview surveys are able to produce data about persons, and the total number of episodes within a time period, irrespective of the locations at which services may have been received. To obtain information about multiple episodes and services for the same person from administrative records requires elaborate numbering systems and complex methods of record linkage. This may be much less of a problem in countries which have nationalized health care systems than it is in the USA where the high use of private medical resources, coupled with the high mobility of the population, provides for no central focus for record flow and linkages for individual persons.

The content of interview surveys is extremely flexible. Although it is unwise to overload a questionnaire with too many topics, nevertheless, the variety of subjects that can be covered far exceeds that which can be obtained from multiple record-sources. This is particularly true of social and demographic data, such as income, education, family relationship, ethnic group, and veteran status, which are often not available from records but which make possible valuable cross-classifications and analytic relationships to the health variables. Since interviews are conducted in households, and information is obtained from all members, it is possible to produce data on the basis of household or family relationships. In the analysis of the US survey data this capability has not been exploited as much as many of the users would like, although the relationships between family size and structure, and medical expenditures, long-term disability, and health care received at home have been studied, as have the relationships between data on many health topics and items such as total family income, educational level of the parents, or occupation of the head of the family. These family variables are often more relevant than the same variables for a given individual.

There is still another class of information which is not usually obtainable from record sources but which may be obtained from interviews. In recent years in the USA there has arisen a great deal of interest in the knowledge, attitudes and behaviour of people, and how these and other factors may result in barriers to seeking and receiving health care. This is a very difficult area in which to formulate questions and obtain codifiable responses. Besides, there are some people who feel that it is not the business of a federal agency to be probing into people's feelings and attitudes. For many years no attempt was made to obtain attitudinal data, but because of this growing demand some experimental work and pretesting has been undertaken in this field.

In all, the health interview survey is a powerful tool for the measurement of the social and demographic concomitants of the health picture of a country. There are many data needs that have not been filled, such as data on alcoholism, drug abuse, and other sensitive issues; levels of mental illness; health in relation to the physical environment; health care needs; and the quality of medical care received. Some of these may not be amenable to definition and survey techniques, or in any event they will require much research and testing before adequate data can be produced. Yet the demands for publications, special tabulations, and computer tapes from past and present interview surveys more than justify their continuation into the future.

Paper 14

Survey research in the health information system

L. Moss

14.1. Summary

This paper attempts to describe the nature of the contribution of survey research to a health information system. The view taken is that data derived from appropriately designed surveys and the continuing records of the operations of a health care system are complementary.

Records are obviously essential for basic control and monitoring systems, and they can be used for many evaluation purposes. They relate however to individuals who have come into contact with the system and, by their nature, do not give information about individuals whose disabilities are unperceived, or who for other reasons find the system of health care inaccessible. Survey research techniques can reach these people and help to complete the picture of need. Since they are based on direct contact with individuals or households, they can also provide detailed information about those social circumstances and characteristics which may clarify why needs are unperceived, or do not become effective demand for health care. They can be so organized as to incorporate clinical assessments or other medically defined information, such as the limitations on normal activity imposed by some forms of disability.

Because they can cover whole populations, and not only those who constitute the effective demand for medical care, they can provide estimates of norms of behaviour or limitations of behaviour and when they incorporate medically defined diagnoses or descriptions they can provide analyses of ranges of physical conditions or behaviour which may be useful as norms against which the conditions of individuals can be assessed.

Whilst health services and the statistics they produce will differ in many ways from country to country, it may be feasible to apply survey techniques in a relatively controlled and standardized way on an international basis. This could greatly increase the range of international comparisons of disability and health care services which are available.

In the General Household Survey an attempt has been made to provide data which can be used together with the continuing information available from the operations of the health care system. So far only a limited part of the potential contribution of survey research techniques has been employed. It is to be hoped that over time, whilst maintaining some continuity, the work can gradually become more patient orientated. This would seem specially relevant to a survey, the multi-purpose design of which should permit analyses of disability and health care in relation to a wide range of social variables.

14.2. Introduction

This paper starts from two main assumptions. First, developments in health care will impose responsibilities on governments to adjust their health care systems, however organized or financed, to the needs of their populations, and to have available such information as is needed to show whether or not this is being done. Secondly, it is clear that a great deal of the information required for an appropriate health information system will come from the working of the health service itself. Further, it is assumed that this kind of control information, derived from the workings of the services, will be exploited to the full and the scope of this paper has been restricted to consideration of the ways in which survey research, mainly through population samples, can complement and supplement this continuing system.

14.3. Definitions

It is necessary to define what a health information system should try to measure. Two different definitions have been advanced by British health researchers. Alderson (1976) takes two main dimensions: *need* which he divides into unperceived and perceived, and *demand* which he divides into unmet demand and met demand. A distinction is thus drawn here between disabilities which are not known, those which become known and for which treatment needs are unmet and those which are treated by the health care system. Marson, Morrell, Watkins, and Zander (1973) use different dimensions: *accessibility*, or the extent to, and ease with which illness is brought to the attention of the health care authorities, and *acceptibility*, or whether an episode is dealt with in a way which is satisfactory to the patient. For Marson *et al.* therefore, the main purpose of a health information system must be to identify the needs of medical conditions which can be controlled or alleviated; a further dimension is added in which health services are required to use to the maximum available resources to meet these identified needs.

If these two sets of definitions are taken together, criteria can be developed which help to define possible objectives for a health information system.

(i) It should measure accessibility by the extent to which needs are perceived, become demand and are met. Unperceived need and unmet demand then become measures of the inaccessibility of health services.

(ii) An information system is efficient if it permits identification of needs which can be met; and areas where need exists, is unperceived, cannot be met, or is not being met because of the way resources are at present being deployed.

(iii) The acceptability of health care, it must be remembered, will always reflect the extent to which the population is conscious of its need for health care; and this in turn will very much depend on the level of health care to which it has been accustomed. So here is a major factor in deciding whether needs are perceived or unperceived, and hence another measure of failure by the system to identify need.

14.4. Information for management purposes

From the viewpoint of the managers of health services there are three kinds of purposes for which they need information.

Monitoring

The first is monitoring. This has different connotations: to some it implies a policing of the system so as to identify failures to perform; but more simply it can be considered as an attempt to answer the question—what are we doing and what does it cost in resources to do what for whom? For this purpose a limited range of indicators of output and input, which can be provided from routine record data, is selected; they must be documented for the whole health care system, and can then be used to identify areas of special interest. It must be emphasized that the whole system should be covered for monitoring purposes because only by reviewing what is happening in the whole can these areas of special interest be picked out. This wide coverage of data, which basically derive from recording the activities of the services, at the places where they happen, has certain similarities to a census, and factors which affect the scope of the study, type of questions, convenience of collection and analysis, apply to monitoring also. Use is being made of data that can be obtained and managed on a very large scale, and this will have concomitant limitations. The hospital in-patient data system in England and Wales is one example of this type of monitoring usage; another example is the regular analysis of prescriptions.

Evaluation

The second management purpose, which must be distinguished from monitoring, may be called evaluation; and here the question is–how well are we doing? Information, especially that produced by the continuous monitoring system, is used to compare, regularly and systematically, the performance of the health services against needs or demands for health care (estimated from other information sources); comparisons are made over time or between administrative areas, or between different types of services. From UK data, comparisons of the costs of treating patients in teaching and other kinds of hospitals are available, as is information on the number of bed days, for standard classifications of types of illnesses, in different parts of the country. It is also possible to compare the issue of prescriptions in single-doctor practices with that in partnerships, and so on. In general, this type of system evolved for monitoring and the associated evaluation establishes its own norms and enables specific parts of the health service to be compared with average performances. It may also be possible to incorporate information from special case studies on the characteristics of particular types of health care facilities into the analysis of the data derived from the records of the health care system.

Research

The third management requirement is research, which attempts to answer the question–how can we do better? This must be sharply distinguished from monitoring and evaluation; whilst there is continuous data coming from records and used for monitoring and evaluation, research of course is not so controllable. It will depend substantially on the interest, imagination, and capacity of researchers and it essentially involves standing apart from the system. It need not be, and generally is unlikely to be, continuous. Research, almost by definition, involves questioning objectives; the criteria used for evaluation; or the validity and utility of the data collected in monitoring. It may be concerned with examining or testing experimental approaches and new procedures, but the basic assumption is that some kind of change in the health services may be required.

14.5. Routine data and survey data

If this description of the management information requirements for supervising a health service is accepted and the criteria for a health information system, described earlier, are considered, it is feasible to ask to what extent data generated by the health service records meet the requirements, and to what extent supplementary activities, and here only survey research is discussed, may be needed to enable the information system to produce what is required. A system which records what is now being done will give us regular indications of that part of demand which is met by the services, and perhaps some of the demand which is known to exist but not met; waiting lists for hospital admissions may provide some of the latter indications. Such a system does not by itself give us a measure of that part of perceived need which is not met, and even less does it offer any direct measure of needs for health care which may exist, but are not perceived. If this is so we cannot use the routine record data to measure the complete range of accessibility, and the information system deriving from current operations needs to be supplemented if it is to give us the more complete picture.

Continuing recording systems must be selective, they cannot record all items of information which are useful or even necessary for detailed appraisal, and are of limited use for research purposes for this reason. This does not mean that they cannot fulfil most information requirements for monitoring and evaluation purposes; but they cannot cover the socio-economic background of patients, or of the practitioners with whom the patients come in contact. And since it is only through consideration of the social context that the way in which need for care moves from being unperceived to perceived, and from need to effective demand, can be understood, it is essential to have some way of examining disease states in the full range of social circumstances which may be relevant.

Ad hoc and continuing surveys

Survey techniques can certainly help in supplementing routine data, and in collecting a wide range of data on individuals so as to illuminate relationships between socio-economic factors and health. However, different types of surveys may be required. Specially organized surveys are extremely useful for filling specific gaps in information, but there is a limit to the numbers and scale of special surveys which can be undertaken. Furthermore, they give a picture at one point in time and if they lead to changes in services, or if the system or public opinion are changing anyway, then they become out-of-date. (See sections 14.6 and 14.7 for examples of *ad hoc* surveys). There is a need for continuing study of some central features of health and health care, and survey techniques can be of use here too. If continuous surveys are to supplement other data, they must be organized through a close working relationship with the statisticians and health service management responsible for the output and analysis of the continuous routine data. And if they are to be of maximum use, they should also produce information which is relevant to the interests of medical researchers. Section 14.8 describes the General Household Survey which has been developed in the UK to provide this type of information.

14.6. Survey of the handicapped and impaired

This survey (Harris 1971) was undertaken as a consequence of increasing public concern. Under an Act of Parliament of 1948 local authorities in England and Wales were obliged to 'keep a register of those who apply for assistance because of physical disablement'. Such registers record met demand for help but questions were being raised as to the extent to which these records measured actual need. The survey had to locate disabled persons and since a physical impairment can cause various levels of handicap, it was necessary to identify those with impairment who also suffered handicap. A large scale postal enquiry addressed to a representative sample of 250 000 households discovered a sufficiently large number of handicapped people to provide the basis for a detailed follow-up interview survey. Impairment was defined as the 'loss or reduction of functional ability', and handicap as the 'disadvantage or restriction of activity caused by disability'. This was essentially a functional definition which was operationally feasible for survey research techniques and the postal stage permitted estimates of the number with some kind of physical impairment and their geographic and demographic distribution. The total of those with physical impairment was just under 8 per cent of the total population over the age of 16 years.

TABLE 14.1. *Proportions of people with different degrees of handicap who are listed on local authority registers*

Degree of handicap	Total number of people found by survey	Percentage registered with local authority
Very severe (1-3)	652	17.9
Severe (4-5)	1 420	10.9
Appreciable (6)	2 457	6.7
All handicapped (1-6)	4 529	11.8
Minor/no handicap (7-8b)	7 734	2.7
All impaired	12 738*	5.2

*including persons in categories 4-8 who could not be classified.
(After: Harris 1971).

One of the possible forms of government action was an attendance allowance for those most severely handicapped. It was necessary therefore to identify those so handicapped as to need others to supply most of their wants. Since the extent of handicap is a continuum it was decided to devise an index of handicap based on ability for self care. Another aim was to examine the extent to which various health and welfare services were helping to support handicapped people. Detailed questions needed for all these purposes were designed and put to people identified as suffering some form of handicapping disability in a structured interview.

Table 14.1 shows the distribution of handicap between nine categories of severity devised from the detailed questions asked in the interview. It will be seen that about one in eight of all the handicapped were registered; one in five of the severely handicapped were registered compared with about one in sixteen of those defined as 'appreciably' handicapped. The 'very severely' handicapped, those who are bedfast, were less likely to be registered than those who could, if accompanied, get out of the house. The regional variation in proportions in the different handicap categories who were registered were substantial. Clearly in so far as registration recorded help given, then for very large proportions of the disabled appropriate care was not accessible at the time of the survey; and neither were those in need of care known to the authorities. A more recent Act of Parliament, following on the survey, imposed an obligation on local authorities to find out the size and nature of the problem in their areas. It was found from the survey that many of the disabled who were not formally registered might still be receiving some help from local authorities. The explanation was that the department responsible for registers was not the department giving help. One wonders to what extent this kind of under-recording of health care activities is inevitable without integrated statistics at the local level.

In fact a great deal of medical attention was being given; about half of the very severely disabled had regular medical attention from a general practitioner and smaller proportions of those with lesser degrees of disability. As Table 14.2 shows, however, nearly 30 per cent of all the handicapped had not seen their doctor within 3 months of the interview. It is highly probable that a medical diagnosis would have been made at some time, and therefore it was thought practical to ask interviewees questions about their impairment which permitted some estimates to be made of the main cause. These are given in Table 14.3, broken down by category of severity. It will be seen that some groups of impairment make a very big contribution to the total.

TABLE 14.2. *When the elderly and non-elderly handicapped last saw their general practitioner (regular and non-regular visits)*

General practitioner last seen	Handicapped people (categories 1-6)		
	Aged 16-64 %	Aged 65 or over %	All ages %
Within last week	9.7	11.1	10.6
2 weeks to 1 month ago	37.9	41.1	40.0
Over 1 month to 3 months ago	22.0	19.9	20.7
3 months to 1 year ago	22.0	19.8	20.5
Not within the last year	8.4	8.1	8.2
No. on which % based	1 539	2 928	4 467

(Source: Harris, 1971)

Since detailed questions could be asked about the extent and nature of the effects of disability, the survey made it possible to describe the living conditions and circumstances of handicapped people in some detail: their mobility and means of communication, methods and costs of coping with household burdens such as laundry and the care of young children, leisure activities and so on.

TABLE 14.3. *Estimated numbers of men and women in various categories of handicap by main cause of impairment (in the total population)*

	Category of handicap			
Main cause of impairment	1-3	4-6	7-8	All categories
Infective and parasitic diseases	*	7 500	22 000	30 000
Neoplasms	2 900	8 400	16 000	27 000
Allergic, endocrine, metabolic and nutritional diseases	2 400	11 000	38 000	51 000
Diseases of blood and blood-forming organs	*	13 000	14 000	28 000
Mental psycho-neurotic and personality disorders	6 000	24 000	68 000	98 000
Diseases of central nervous system	63 000	125 000	172 000	362 000
Diseases of circulatory system	16 000	118 000	358 000	492 000
Diseases of respiratory system	4 300	58 000	221 000	282 000
Diseases of digestive system	2 700	23 000	57 000	82 000
Diseases of genito-urinary system	3 100	14 000	18 000	35 000
Disorders of sense organs (excluding blindness)	1 900	50 000	153 000	205 000
Diseases of skin and cellular tissue	*	*	17 000	20 000
Diseases of bones and organs of movement	45 000	486 000	656 000	1 187 000
Congenital malformations	*	3 900	12 000	16 000
Injuries	*	30 000	83 000	114 000
Senility and ill-defined conditions	17 000	29 000	76 000	122 000
Amputations	2 400	28 000	98 000	129 000
Blindness	3 900	15 000	53 000	72 000
All persons with some impairment	157 000	973 000	1 941 000	3 071 000

*Sample number too small to estimate.
Estimates under 10 000 rounded to nearest 100; estimates over 10 000 rounded to nearest 1 000.

(Source: Harris, 1971)

The survey effectively screened a representative sample of the whole population covering both those people on registers—who were in contact with medical and local authority services—and those not on the record. Thus it established the level of unmet need for care, if it is accepted that severe degrees of physical disability imply such a need. This could be contrasted with the help received at the time of the survey and conclusions drawn about the kind of resources required if care was to be provided for those not getting it. The survey enabled calculations to be made of the cost of cash benefits to be given for different degrees and conditions of severity of disablement and it has been followed by many local surveys designed to help local authorities to take a more active role in caring for the disabled.

The criteria used for distinguishing degrees of severity were social rather than medical but it is also possible to use survey techniques in a design which incorporates data collected according to medical criteria.

14.7. Surveys of dental health

Adults

The Dental Estimates Board collects a great many data relating to courses of treatment given by dentists but this again relates only to people who go to dentists. The first survey in the series on dental health (Gray, Todd, Slack, and Bulman 1970) covered those aged 16 years and over in a representative sample of individuals living in private households. The enquiry consisted of an interview with the selected individuals followed by a dental examination. Since it was known that some variation in the results of examination by different dentists might be expected a training programme for cooperating dentists was organized as well as the normal training and briefing procedures for interviewers. The collaboration of dentists and their supervision was achieved through dental schools.

The contact with individual informants was initiated by interviewers from the Government Social Survey who asked about their perceptions of their dental conditions, attitudes to treatment, dental hygiene and history of contacts with dentists. The interviewers then introduced the question of examination by dentists. As a result about 77 per cent of the selected sample were actually examined in their homes. The record of the examination was made by the interviewers who thus obtained a complete account of the whole process- both answers to a detailed interview and a standardized physical appraisal by a dentist.

The results provide first a simple measure of the dental health of the community--the proportion of people with no natural teeth. In 1968 amongst adults of 16 years and over in England and Wales the proportion was 37 per cent. Regional variations were marked (Table 14.4); there was a higher proportion of females than males; and there was a wide social class difference range, from around 15 per cent in the professional groups to 47 per cent amongst unskilled workers. The proportion in the USA, derived from the National Health Examination Survey, of those with total tooth loss is half that for England and Wales. However in the most favourable regions in the UK, London and the South-East, the figure was not very different from the US national figure, and among females aged 24-34 years total tooth loss was less than for the comparable age and sex group in the USA.

TABLE 14.4. *Proportion of people with no natural teeth in various regions*

	The North	Wales and the South West	Midlands and East Anglia	London and the South East	England and Wales
Percentage of people with no natural teeth (edentulous)	45.5	43.2	33.9	28.4	36.8
No. of adults (aged 16 years and over) studied	864	431	629	1 008	2 932

(After: Gray *et al.* 1970)

Secondly, the survey produced data on the extent of tooth decay and treatment received. It seems that marked changes are taking place amongst the younger age groups, who will most influence the situation in the future. And it seems that changes in the regularity with which the young visit the dentist are strongly associated with their ideas of the kind of treatment they prefer. One paradox thrown up by the survey is relevant to consideration of the dental resources which will be needed as attitudes and preferences change. Whilst the proportion of regular attenders is highest in London and the South-East this is also the region which has the lowest number of people per dentist. The reverse was found in the North and Wales where the population per dentist is highest and the proportion of regular attenders is lowest: as a result the number of regular attenders per dentist is much the same all over the country. Clearly any marked changes of attitudes in the present worse areas could put great pressure on dental resources in those areas.

One result of such a survey is to provide a series of national norms for levels of health and treatment against which can be set the results for particular regions, social groups or different behaviour groups. These norms provide some basis for priorities in health planning.

Children

This point is brought out most clearly in a subsequent survey of Children's Dental Health (Todd 1975). Here the order of events was somewhat different. A sample of school children in England and Wales was selected on a scale large enough to give analyses by year of age from the fifth to the fifteenth year. They were examined by dentists and then interviews were carried out with the mothers of children aged 5, 8, 12, and 15 years: 95 per cent of the selected children were examined and 91 per cent of the mothers of the sub-samples were interviewed. The examination provided a clear picture of the changing patterns of dentition between 5 and 15. For example the eruption patterns for permanent teeth and the extent of variation in the age at which particular teeth appeared could be traced year by year. In many fields of medical interest it is important to know the range of variation which may be expected, 'norms' in such cases should not be single figures but rather ranges: this survey provided 'norms' for children's dental history.

The children's survey also gave, of course, very much the same data on the extent of tooth decay and treatment received as the adults' survey. By eleven years of age, over half the children in this age group had some active decay in their permanent teeth and 18 per cent in the same age group had had one or more permanent teeth extracted for decay. The dental examination looked not only for decay but also at indicators of the possible need for dental attention, such as the segments of the mouth which were crowded indicating need for orthodontic care. These detailed data could provide the basis for costing the additional dental attention needed if the most serious deficiencies were to be dealt with.

But perhaps the most interesting part of the survey was the attempt made to relate information derived from the mothers' interview with the actual condition of their children's teeth. Since the adults survey had shown that changes in the attitudes and preferences of the young adult might be expected to have far reaching effects on the dental condition of the future population then clearly it is of some importance to discover the effects of mothers' attitudes and behaviour on children's dental condition. The physical condition of the children's teeth could be related to many characteristics of the mother and of children's upbringing. The survey showed that the younger the child, the more likely is the mother to be herself a regular attender at the dentist; and that the mother's attendance is to some extent related to the child's dental condition. This was true in all socio-economic groups and regions of the country. The mothers of the younger children seemed to be a little more knowledgeable about the ages when the first permanent teeth may be expected. Judgement about how well-informed the mother was on such matters came from the comparison of her ideas with the normal history of dentition derived from the examination part of the survey.

The great majority of mothers identified eating sugar and sweetened foods as a cause of decay, and the survey produced clear evidence of the effects of such habits on the dental condition. Fluoridation was mentioned spontaneously by negligible proportions; although nearly all claimed to have heard about it when prompted, appreciable numbers could not say what effect it has. Mothers' views of how children feel about visiting the dentist were very much affected by their own *feelings* on the subject and probably more so than by their own dental condition.

The survey of the handicapped was dealing with a known condition. The disability was clearly perceived and the need for health care could be identified by measurable disability. Clearly the onus here was on the health authorities to take action. It might be said that demand existed but in Alderson's terminology was 'unmet' because inadequate attempts were made to meet it. The survey showed that the health information system could, through its use of survey techniques, make demand evident in sufficient detail to identify the appropriate action. In the dental condition survey the situation investigated was apparently different. Clearly for large sections of the population need for dental care was not perceived, and hence had not moved to the stage of becoming 'demand' for dental care. The picture of the dental condition of the population drawn by the survey showed that in some regions of the country considerable decay and loss of all or many teeth was accepted as part of the 'natural' situation. The threshold between physical need as revealed by clinical judgement and demand for care in any sense was very high. At the same time the situation was clearly changing, as shown by difference in age groups, so conclusions about the adequacy of dental care facilities based on the present situation would not be valid for the future. By the same token since available statistics emerging from the continuing system related to present dental habits they, too, would not provide a sound basis for estimating future needs if indeed the changes in attitudes and habits continue.

14.8. The General Household Survey

The first continuing health survey carried out in the UK of this sort was the Survey of Sickness 1943-1952 (Logan and Brooke 1957). It was concerned only with self perceived morbidity and use of medical care and, since the National Health Service was inaugurated in the middle of this period, it provided unique data on some of the consequences of the new system. Since that date the USA has launched much more ambitious National Health Surveys and work has begun in other countries.

Attention here will, however, be concentrated on more recent work done in the UK as part of the continuing General Household Survey (GHS) which began in 1971 (Office of Population Censuses and Surveys 1973). This is a multi-purpose survey which covers employment, housing, income, education, health and health services as well as other topics which change from time to time. Only some aspects of these subjects can be covered but there is no reason why these should not change so that, in the course of a period of years, many aspects could be covered; and if they were treated periodically, series could gradually be built up. But the more important point is that simply because these different topics are each covered for every household in the sample it becomes possible to examine a wide range of interrelationships. This could be important for many policy decisions on health care. The sample covers about 15 000 households in any one year. An attempt is made to interview every adult in each household so that the number of interviews carried out is about 35 000. The health section has developed over time and may change in accordance with policy interests of those for whom the data is collected—the survey is designed to meet some of the needs of eight different government departments.

14.9. The health section of the GHS

The Department of Health and Social Security—the major customer for the health section of the General Household Survey—originally envisaged the survey mainly as a supplement to official statistics, providing information on the use of health and social services in relation to demographic variables not included in their own statistics, but also partly as a source of information about that large part of illness which is not presented to a doctor or a hospital and hence is not reported in any official records.

Therefore the core topics of the GHS health section—that is, those topics that have been included in the survey from the beginning and which in some form or other are likely to remain in it permanently—fall broadly in four areas: activity limitation caused by sickness, consultations with general practitioners, use of certain health and personal social services, and visits to hospitals. Information on these subjects is collected from all adults (those aged 15 years or over in 1971/1972, and 16 years or over from 1973 onwards) and in addition mothers are asked about their children, so that a picture of the health state of a complete household is obtained. It is important to remember that the GHS is a survey of private households and does not cover the institutionalized population whose sickness and service usage patterns, in particular those in geriatric hospitals or long-stay institutions, may differ from the patterns of people living in the community.

Sickness

It is partly the extent to which people feel ill that motivates them to seek advice or treatment, but 'feeling' ill or well is difficult to measure. However, its perception can be shown by people in the effect it has on their daily activities; and although answers to questions about behaviour are subject to environmental influence, they are nevertheless more objective than an informant's opinion about his health state. It seemed therefore that Departmental needs could best be met by examining limitation of activity caused either by long-standing (chronic) or short-term (acute) sickness, and it must be emphasized that neither of these measures was designed to present total sickness prevalence rates in the population as a whole.

Chronic sickness is defined in the GHS as a long-standing illness, disability or infirmity which limits an individual's overall activity level. Because a great deal of the illness reported in the GHS has not been presented to a health agency, comparison with other data sources is difficult, nevertheless such an attempt must be made. The first British data source that springs to mind is the Survey of the Handicapped and Impaired discussed in section 14.6. However, this study concentrated primarily on impairment rather than long-standing illness and although the relative age/sex patterns found from the two surveys are broadly similar, the GHS definition draws more people into its net in every age group. The steep rise in the chronic sickness rates per 1 000 persons with age, suggests a comparison with data on mortality. For example the widowed, divorced, and separated reported higher chronic sickness rates than their single or married counterparts and this is consistent with mortality experience. Mortality statistics also show an inverse relationship with social class and a similar relationship emerges from GHS data on chronic sickness when analysed by broad socio-economic groups. The data in Table 14.5 is presented in age-standardized form, and the actual or observed rates for each group have been expressed as a percentage of the expected rates for each group (that is, the rates that would have obtained if each group had experienced chronic sickness at the national rate). These age-standardized ratios show that professional men reported only 75 per cent of their expected rate of chronic sickness, while unskilled men reported 50 per cent more than expected.

TABLE 14.5. *Chronic sickness, by sex and broad socio-economic group; age-standardized, observed rates as a percentage of expected rates*

Broad Socio-economic Group	Total	Males	Females
Professional	72	74	69
Employers and managers	76	78	75
Intermediate and junior non-manual	85	86	85
Skilled manual (including foremen and supervisors) and own account non-professional	104	103	105
Semi-skilled manual and personal service	119	120	119
Unskilled manual	134	156	118

(Source: Office of Population Censuses and Surveys 1975)

In times of world-wide rising unemployment the problems of the chronic sick give particular cause for concern, and the wide range of demographic variables contained in the GHS enable this to be highlighted. Table 14.6 shows that in 1971 and 1972 the unemployment rate amongst chronic sick men of working age was over twice the rate for all men of working age, and this trend was more evident in middle-aged men, particularly in 1972.

TABLE 14.6. *Males seeking work as percentage of male work force, by age and whether chronic sick*

	1971		1972	
	Chronic sick males	All males	Chronic sick males	All males
	%	%	%	%
15-44 years	7.9	3.6	10.7	4.9
45-64 years	8.9	3.9	12.3	3.7
Total	8.5	3.7	11.6	4.4

(Source: Office of Population Censuses and Surveys 1973 and 1975)

Again, a survey such as the GHS can show that the strong association of chronic sickness with age and widowhood was, as might have been expected, carried into exacerbating factors such as low income, loneliness and, to a lesser extent, poor housing.

Acute sickness is defined in the GHS as restriction of the level of normal activity caused by illness or injury at any time during a two-week reference period. Normal activities include leisure activities as well as school attendance, going to work or doing housework. Those with a chronic condition who also suffered acute illness during the reference period are included. Informants are asked on how many days during the two weeks they were restricted; whether their illness or injury confined them to bed or caused them to be absent from work or school; and whether this absence carried a medical certificate or not.

The social and economic consequence of illness can be most clearly demonstrated in the number of days lost from work, and the advantage of GHS data is that it can cover the entire population as opposed to those official statistics which are abstracted from sickness benefit claims; these relate only to the fully insured population, and therefore exclude most married women and certain occupational groups of workers. In addition analysis of GHS data can include days of absence not certified by a doctor, which did not appear in official statistics since they do not qualify for sickness benefit. The DHSS figures suggest that the average female employee had more days of certified absence than the average male employee, but as GHS data presented in Table 14.7 show, when married women are included together with all days lost, both certificated and uncertificated, the reverse is true. Not only are women no more likely than men to report absence from work due to illness or injury, but on average they took fewer days off. Table 14.7 also shows that male blue-collar workers, in particular men in unskilled occupations, have much higher absence rates than male white-collar workers.

There has been a tendency for sickness absence to increase over the last twenty years. This is contrary to what might have been expected, in the light of Table 14.7, from the decreasing ratio of blue-collar, manual work to the total labour force. The GHS provides data to examine some of the social factors which may affect this trend; for example, analysis of sickness absence by sick pay coverage shows that the provision by employers of sick pay schemes does not tend to increase the number of days lost from work, whereas analysis by job satisfaction suggests that where this is lacking, an individual's motivation to work may be reduced.

Use of services

In the UK the general practitioner is the usual point of first contact with the medical services of the National Health Service, and the GHS covers many aspects of these contacts: the number of consultations in a two-week reference period; on whose behalf the consultation was made; whether the consultation was made under the National Health Service or paid for privately; and the location of the consultation. Fig. 14.1 shows how home consultations increased with the age of the informant, until amongst those aged 75 years or over almost two-thirds of all consultations involve visits to people in their homes.

TABLE 14.7. *Absence from work due to illness or injury in a two-week period, by sex and broad socio-economic group, showing rates per 1 000 persons and average number of days lost per person per year*

Broad socio-economic group	Rates per 1 000 persons			Average number of work days lost per person per year		
	Total	Males	Females	Total	Males	Females
Professional	21.1	19.3	26.1	3.1	3.0	3.4
Employers and managers	39.2	39.9	38.0	6.2	6.8	4.9
Intermediate and junior non-manual	48.3	39.9	56.2	6.0	5.3	6.5
Skilled manual (including foremen and supervisors) and own account non-professional	56.3	57.0	54.7	9.4	10.0	8.3
Semi-skilled manual and personal service	67.7	75.0	57.7	10.5	12.8	7.4
Unskilled manual	98.9	122.0	57.3	17.6	22.6	8.5
Total	54.5	55.3	53.1	8.4	9.3	7.0

(Source: Office of Population Censuses and Surveys 1975)

It is manifestly important when planning the distribution of health resources, to know which sections of the population are the heaviest users; various writers have suggested that in the UK, the lower socio-economic groups make greater use of the services of general practitioners than do other groups. At first sight, the GHS data tends to support this hypothesis in relation to males of working age, for men in semi-skilled and unskilled occupations are more likely to consult a general practitioner and to have higher annual consultation rates than other groups of that age span. However, this does not take relative morbidity levels into account and, as Table 14.5 showed, the semi-skilled and unskilled have very much above average rates of chronic sickness. If a relatively crude use/need ratio is devised by dividing the rates per 1 000 persons consulting by the rates per 1 000 persons reporting chronic sickness (both age-standardized), the data suggests that in relation to chronic sickness, the semi-skilled and unskilled in fact make less use of general practitioner services than do other groups.

The GHS also covers periods of hospital in-patient treatment and attendances at out-patient departments in a three-month reference period. The length of the reference period is dictated by statistical need to cover a significant number of episodes, particularly in the case of in-patient treatment. Even with this extended reference period however, the number of in-patients in the GHS sample is too small for detailed analysis. Questioning about out-patient attendances produces larger numbers, but the problem here is one of definition: to the general public the out-patient department may mean any one of a number of different departments they go to, having entered a main door of a hospital marked 'out-patients'. Thus while GHS results for 1971 and 1972 indicate that unskilled males report a higher rate of out-patient attendance than males of any other group, it is not yet possible to say whether this represents equity of access across the whole range of out-patient facilities, including specialist advice and care to ambulatory patients, as well as casualty/accident departments, and ancillary services such as X-rays, and physiotherapy.

The twin problems of definitional imprecision and small numbers have also bedevilled attempts by the GHS to collect data on the community health and personal social services such as the community nurse, the chiropodist, and the social worker. Many of these services are used by minority groups, amongst whom the elderly or the inarticulate figure largely, who find it difficult to identify in official terminology the name of the service they have received or to remember accurately the number of times they were visited in the one-month reference period. Nevertheless the GHS at the moment is the only source for relating use of these services to the kind of information on persons and households which is collected elsewhere in the survey, and the Department of Health and Social Security has made fairly extensive use of it in attempting to define 'packages' of care received—by the elderly, for example. Analysis by income level of six domiciliary services used by the elderly suggested that the poorest households (which are most probably single person households) made greater use than others of the domiciliary services. However, even among the oldest age group in the lowest income band two-thirds claimed they had not been visited by any of these services in a one-month reference period.

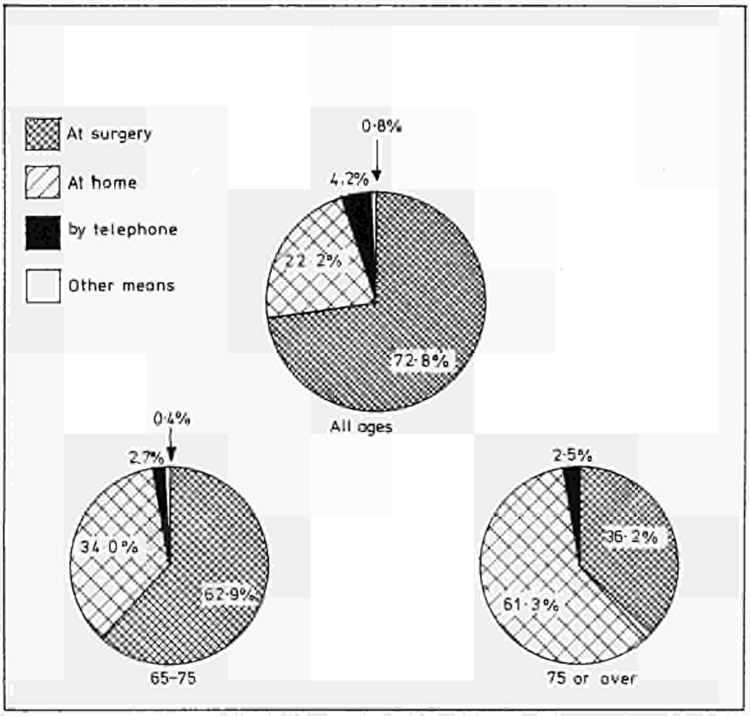

FIG. 14.1 *The proportions of consultations with general practitioners within the NHS conducted at the patient's home; in the general practioner's surgery; or by telephone, during a 2 week period in 1971, for patients of all ages, those aged 65-74 years, and those aged 75 years and over.*

Cause of sickness and cause of consultation

Probably the most difficult data of all to collect in the GHS health section is that relating to the cause of chronic and acute sickness and the cause of consultation with a doctor. The approach adopted by the GHS is a relatively simple one whereby the interviewers ask what was the matter with informants and what the consultation was about. The resulting information is coded according to the 4-digit codes of the ICD. A great deal of methodological work has been done in this field all over the world which underlines the difficulties of collecting morbidity information from population surveys. Obviously it does not necessarily conform with clinical diagnosis. The reasons for this are too well known for detailed discussion in this paper, but briefly they stem from the fact that informants may not yet have consulted a doctor, or if they have, the doctor may not have fully discussed the illness with them, in which case the condition may be self-diagnosed or interpreted by a relative or a friend. Also in the family situation which characterizes the GHS interview, there are certain conditions which an informant may be unwilling to discuss with an interviewer. However, the National Morbidity Survey conducted by the Royal College of General Practitioners and the Medical Statistics Division of OPCS—a survey which collected national statistics about morbidity as seen in general practice from a sample of general practitioners (Office of Population Censuses and Survey 1974)—offers the opportunity of comparison with GHS results. Despite the differences in methods of data collection, the distribution of consultations by sex and broad diagnostic groups shows a remarkable degree of similarity between the two surveys. The most important difference between the two sets of data is an under-reporting in the GHS of about 50 per cent for neoplasms and mental disorders, which might well be expected in a population sample, for the reasons outlined earlier.

14.10. Developments since the start of the GHS

Insertions of special sections on a once only basis

One of the advantages of a continuing survey such as the GHS is its ability to insert new topics when urgent policy needs arise, although the necessity for keeping the interview length within bounds in order to maintain a high response-rate and maintaining a shape and flow to the interview must always be borne in mind. One of the developments in 1972 was the insertion of questions on smoking habits. It was clear from the outset that if the questions on smoking habits were inserted before the questions on chronic and acute sickness, the latter data might be prejudiced, but the converse might also be true if the questions on smoking followed the health questions. For example, a heavy smoker with bronchitis might tend not to report his bronchitis if he has first been questioned about the number of cigarettes he smokes; and conversely, if he has just described his bronchitis in detail, he may report a lighter smoking pattern. Since it was originally envisaged that the smoking questions would be included for perhaps two years and re-introduced at a later date, it was thought preferable not to risk biasing the continuing questions on health. Thus it is possible that tobacco consumption data in the GHS is under-reported. The 'family fireside' interview situation also creates problems in asking adolescents about their smoking habits, for many of them may be questioned in front of disapproving parents, and the GHS has attempted to counter this by giving 15-17 year olds a self-completion form on smoking. Fig. 14.2 illustrates one of the most noteworthy results from the smoking section and shows that after allowance has been made for age differences between the groups, men in unskilled occupations in 1972 were twice as likely to be current cigarette smokers as men in professional occupations. The relevance of this finding to mortality and morbidity rates, sickness absence, and health service usage is obvious.

In the fourth-quarter of 1972, a number of questions about medicine taking, designed primarily to measure the usage of aspirin in the population, were inserted at very short notice in the health section. It was thought, at that time, that results of research would shortly be published to show that aspirin, because of its tendency to inhibit platelet aggregation, might reduce the likelihood of thrombosis, and the DHSS was concerned that the level of aspirin usage should be known before and after the widespread publicity, which was expected to follow, changed patterns of consumption. In the event, the results of the research published were somewhat equivocal and received almost no publicity. However, the circumstances offered the GHS an opportunity to demonstrate the flexible nature of the survey and to gain some experience in developing questions in the important area of self-medication.

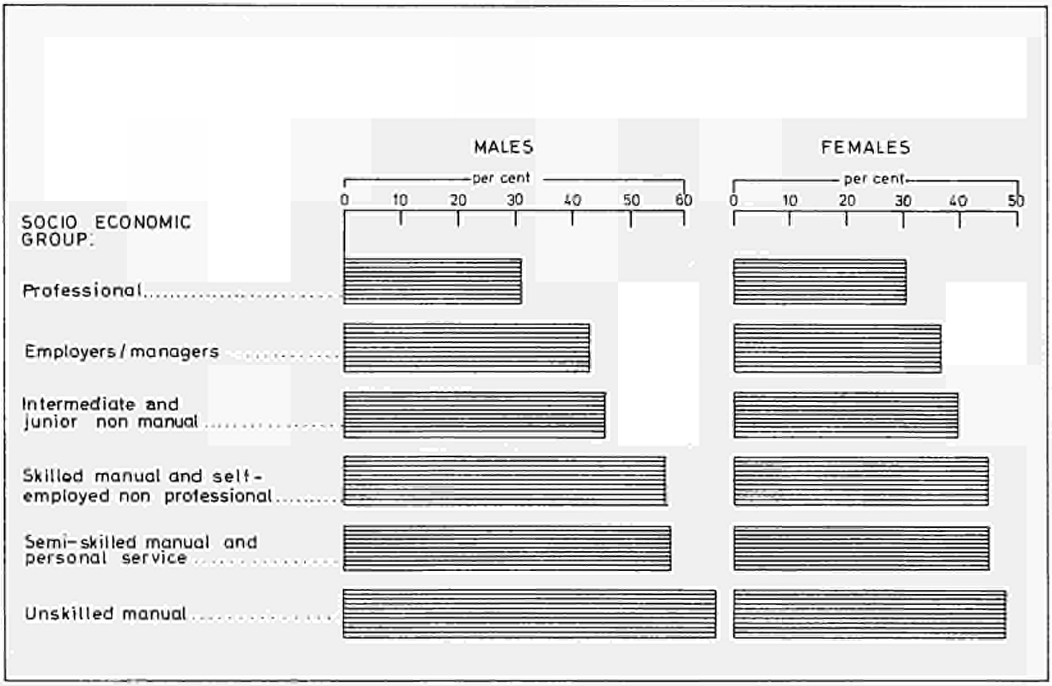

FIG. 14.2 *The proportions of persons aged 15 years or over in various socio-economic groups who are cigarette smokers in Great Britain (standardized for age).*

Questioning on out-patient attendances has been expanded recently to identify use of the different facilities provided and also to explore the phenomenon of self-referral which seems to be on the increase—for what reasons are what kinds of people short-cutting the normal channels of primary care and creating work-load problems in casualty and accident departments.

One of the difficulties facing a continuous survey in its early years is the conflict between the necessity to establish series of data and the need to ensure that the series are based on forms of questioning giving valid results. The GHS has taken the view that constant evaluation and re-appraisal should take place in the early stages so as to build on sure foundations for the future. For example, questioning on chronic sickness has undergone changes which have made year to year comparisons difficult in the initial stages but with resultant improvement in the quality of the data. A great deal of work has also been done to try and improve the quality of the morbidity information by providing interviewers (who are not medically trained) with more focused probes such as 'How does it affect you? how did it start? what does the doctor say is the matter?'

International usage of GHS data

Developments have also taken place in the use that has been made of GHS data. With the consent of DHSS and stringent safeguards on confidentiality, the data has been made available to a wide range of users in academic health research and community medicine. A start has been made on producing international comparisons, which help in evaluating the impact of differing financial arrangements on the take-up of health services, and in examining the advantages and disadvantages of alternative policies. Professor Andersen of the Center for Health Administration Studies at the University of Chicago is currently comparing utilization patterns between the UK and the USA, and discussions have taken place with the Long Range Health Planning Branch of Health and Welfare Canada who are making preparations for starting a Canadian Health Survey. Contact has been made between the GHS unit and CREDOC in France. A great deal remains to be done in this field and it is to be hoped that this Workshop Conference will provide a stimulus to these efforts.

For the purpose of this Conference, it is relevant to consider the special contribution which survey techniques can make to international study. Since health care varies from one country to another, the routine statistics produced by the health care systems will not for a long time ahead be suitable for comparing many aspects of health or health services. But it is possible to organize household surveys on a standardized basis in many countries. This is already being done in the economic sphere by EEC countries on issues such as labour force and consumer buying intentions. Since methods of questioning and population sampling can be kept constant across national boundaries it should be possible to produce strictly comparable data on many health problems. The Johns Hopkins study involving eleven groups in seven countries is a very ambitious example of international collaboration in the application of survey techniques in medical research which should provide very valuable experience for any European endeavour of this sort.

14.11. What of the future?

Reference has been made to the problems of the small numbers, for example of in-patients and users of community services, picked up in limited reference periods. Aggregation of data over years is one possible solution, provided that the organization of service provision is not changing too rapidly. Another answer might be to sample some groups more heavily than others, such as at-risk groups like the elderly or families with young children, but this creates sampling problems and difficulties at the computing stage when reweighting for national estimates. A longer term alternative might be a radical restructuring of the health section, which would take a more open-ended and people-oriented approach, rather than the service-oriented approach which underlies the GHS at the moment. People might be questioned about what happened when they became ill; who they first talked to about it; whether they took any advice or bought any medicine over the counter; how long was it before they saw a doctor (if they did); what was his advice and did they take it; if they went into hospital, what happened when they came out and who looked after them; did they receive any help from community or local services, and if not was there any help that they had felt they needed. This approach might mean a certain loss of precision in the data in that it would mean taking people further back in time than the reference periods in the present GHS (although these would also have to be retained for comparability), but it might present administrators with a more integrated picture of the way the National Health Service functions from the users' point of view, and show more clearly why people with similar illnesses have varying patterns of service usage. Questions on the level of satisfaction with the services provided would form a natural extension of this approach. Alternative ways of collecting morbidity information could also be attempted, for example by concentrating questioning on some of the major killing and disabling diseases such as heart disease, bronchitis, arthritis and rheumatism, each in turn for a given period. Standardized questionnaires have been developed by specialist researchers in some of these subject areas based on clinical testing. There seems to be no reason why these should not be incorporated in the health section of the General Household Survey for a long enough period to provide adequate numbers for useful analysis. The full range of standard GHS data would be available for this purpose. Or attention might be focused on presenting symptoms since patients seldom specify a disease when they seek medical advice.

A closer integration of the continuous and *ad hoc* approaches must be striven for, so that sub-samples readily identified in the GHS can be followed up by more detailed, in-depth enquiries. To some extent this has already been done. Individuals with hospital in-patient and out-patient experience were followed-up and questioned about any dissatisfaction they had felt with aspects of hospital life and whether they had taken this up with someone in authority (this was carried out for the Committee on Hospital Complaints Procedure). A sub-sample of disabled earners was identified within the GHS sample and subsequently questioned about their employment experience in relation to their sickness.

Follow-up techniques exploiting the unique potentiality of the GHS to identify many sub-populations with particular characteristics on health and medical experience could be used to compare doctors' and patients' views of incapacity and treatment, or to explore in detail what actually happens—who does what to whom—for certain defined conditions or states of mind.

Finally, whilst a national survey is essential for central planning purposes, a national sample which is manageable and economically viable may not provide adequate numbers for planners at the regional and local level. One possibility might be to develop a form of the GHS which had been tested and tried out by Social Survey, and which could then be carried out by local health authorities in their own areas.

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Paper 15

Health examination surveys—in theory and application

A.J. McDowell

15.1. Summary

This paper discusses health examination surveys from the basis of experience built up in the 15 years during which such surveys have been carried out in the USA. It defines the distinctions between examination and other types of health survey; and the types of data which examination surveys alone can provide. It then covers in some detail the general methodology--planning, data collection, monitoring and quality control, data processing and analysis--of examination surveys; and the specific methodology and problems of the US survey programmes.

15.2. Introduction

Sixteen years ago, Dr. Forrest E. Linder, the first Director of the US National Health Survey, and later the founder of the US National Center for Health Statistics (NCHS), made the following statement:

> 'The failure of health items to establish for themselves a place in the traditional collections of systematic statistics, can be ascribed, not to a lack of appreciation for the need, but to the stubbornly complicated technical problems involved.' (Linder 1959).

This statement is, fortunately, less true today than it was then insofar as it refers to lack of acceptance of established systems for the collection of health statistics. It is quoted, however, because the complicated technical problems referred to are especially characteristic of health examination surveys, and this largely accounts for the fact that they are less common, even today, than are other types of health surveys. In the USA, a series of national health examination surveys have been carried out for the past 15 years; during that time there have been national health examination surveys in only a few other countries, for example, Japan and Colombia, and Canada is about to begin such a programme.

15.3. Definitions

What kind of survey is meant by a 'health examination survey'? In the context of the guidelines for this Workshop Conference, continuous, national (or regional), probability sampling surveys, which cover a broad range of morbidity and health information are the main concern. Consideration of other surveys, obtaining information only from household interviews, or only from the medical records kept by some class of purveyors of health care can be limited similarly. The essential differentiating characteristic of the health examination survey is the primary concern with those kinds of health related data that can be obtained only (or at least optimally) from specially standardized direct medical examinations, including tests and other procedures used in clinical practice. The health examination survey yields data from specified measurements and assessments made by a trained examiner related to the health status and functioning of the persons examined.

15.4. Purpose

Why are health examination surveys needed? They are needed to measure the nature, magnitude, and distribution of the problems of ill-health, and of the impact on people and on society these problems make; to assist in planning health strategies to deal with the problems; to identify relationships that may facilitate research into the aetiology of health problems; and to evaluate the progress of health programmes in meeting defined goals. But all of these needs are general and relevant to other types of health surveys and health statistics systems. Why are *examination* surveys needed? The answer is in the definition of this type of survey given earlier. Because they are designed to obtain data by direct examination of persons selected in the sample, they can provide information on the level of prevalence of specifically defined conditions. They can provide estimates not just of how many people say they are troubled by arthritis or rheumatism or joint pains, but rather of how many persons have chronic rheumatoid arthritis; not just of how many persons have been hospitalized or seen by a doctor for a specific diagnostic entity, but rather of how many people there are in the population who have that disease, including persons in whom the disease has been undiagnosed and untreated, perhaps even previously unmanifest. It is true, of course, that the name, *health* examination survey, might be criticized since the survey actually measures illness rather than a positive concept of health, but this same criticism could be made of most of what are called health statistics.

Another unique value of the health examination survey is that it can fill many needs for three kinds of health-related measurement data: physical measurements, such as height, weight, or skinfold thickness; physiological measurements, such as blood pressure levels, blood haematocrits, or auditory acuity levels; and psychological measurements, such as scores on a test designed to serve as an index of intelligence. In a health examination survey, such measurements can be obtained for every examined sample person. The resultant normative data, or, more precisely, population reference data, are useful in studies of populations (for example, in growth and development work), in human engineering (for instance, in determining appropriate dimensions for school-room desks and chairs), and in examining distribution data to better understand disease (for example, glucose tolerance test results for a general population are needed as a part of the process of determining what is abnormal). Of course, for measurements where abnormality levels have already been established, knowledge of the distribution of that measurement in the entire population surveyed permits an estimate of the extent of the abnormal condition in the population, (an example is the percentage of persons whose uncorrected binocular visual acuity is worse than 20/30, in the Snellen chart notation).

This brief discussion has indicated two broad classes of necessary data which the health examination survey mechanism is uniquely qualified to provide: specifically defined disease prevalence; and distributions of health-related data for the total population surveyed. Obtaining these kinds of data is the basic purpose for conducting health examination surveys. It is frequently suggested that health examination surveys might serve to validate the morbidity estimates from health interview surveys made on the same population. This is not an appropriate purpose: first, because there are better mechanisms for validating interview findings–for example the kind of record check studies carried out on the US Health Interview Survey (National Center for Health Statistics 2/23). Secondly, and more importantly, because the two different health survey mechanisms measure different things. Interviews measure the impact of the morbidity of which people are aware, in the terms they know, and to the extent they are able and willing to communicate; examinations measure a set of signs, responses, observations, and test results, and combine them to produce a diagnosis. Finally, operational considerations related to the differences between optimal survey designs and degree of clustering in interview and examination surveys operate to make their direct combination of dubious value. It should be noted, however, that *within* the health examination survey, data can be obtained which can give some validation or even calibration of specific sets of interview questions and thus contribute to validation of the methodology of the health interview survey. For example, the next examination survey will include the questions used by the interview survey to estimate prevalence of hypertension, and it will be possible to compare response and examination findings.

15.5. Planning

When it has been decided that health data needs exist which can be met only through the mechanism of a health examination survey, there begins the complex process of planning the survey. For the first such survey it is especially important to allow adequate time for careful and thorough planning. It is hard to give a precise estimate of how much time is required in a particular situation, but it is likely that at least a year will be needed. Once the mechanism for health examination surveys has been developed and a country plans to have a continuing series there must still be a long period for planning each of the successive programmes. In that situation, however, it is possible to overlap the data collection for one survey with the planning of the next and, simultaneously, with the analysis of the data collected in an earlier programme. In the USA, the examination survey operates in this manner, which can be characterized as the 'three-level operation concept'.

Assessing the goals and contents of the survey

One aspect of planning is of prime importance, namely, specifying the survey's specific goals or substantive purposes. It is not possible to set forth the exact process by which these will be determined, since this will vary with the situation in a particular country. It is possible to state certain principles which should be followed and to indicate the general pattern used in this process in the USA. With respect to each element to be considered for inclusion in a health examination survey—for example, information on diabetes—the following questions should be answered by the appropriate personnel:

(i) How and for what purposes will the information be used? (Outlines of proposed analyses are desirable.)
(ii) What specific data are needed?
(iii) How can those date be obtained? (What specific tests, measures and questionnaire items are needed, and what level of skill is required of examining personnel?)
(iv) Is the health examination survey the appropriate mechanism to get these data?
(v) Is the expected prevalence level consonant with the ability of the planned survey to determine it within reasonable confidence limits?
(vi) Can the entire process of obtaining these data be adequately standardized?
(vii) What cost factors are involved in equipment, laboratory work, skilled personnel, and so on?
(viii) Finally, if questions (i)-(vii) all are answered satisfactorily—
What is the place of this particular data need in an ordered priority listing with other potential needs?

The appropriate personnel vary with the question asked. For example, for question (i) the head of a health planning agency would qualify, while for (iii) it might be an expert in the medical speciality involved. In the USA the process of determining the conditions to be included in each health examination survey has been a multi-stage effort involving hundreds of institutions, organizations, and individuals. At the beginning, a wide net is cast and opinions are sought from hundreds of health planners, health researchers, medical care providers, and health educators as to the kinds of data, appropriate to this type of survey, that are most needed. Important in this stage is the input from Federal government agencies, particularly the various elements of the Department of Health, Education, and Welfare. Further follow-up contacts are made with respect to some of the suggested items which seem to be reasonable prospects for inclusion, and information is obtained in greater detail so as to answer each of the questions listed in the preceding paragraph. This leads to further stages of consultation and perhaps to convening *ad hoc* meetings of experts in a particular field to assist in determining feasibility and relative priorities. In the end, decisions must be made at the level of the NCHS, but these must be approved at successive governmental levels up to the Office of Statistical Policy within the Office of Management and Budget in the Executive Office of the President.

Factors to be considered

The process of planning a health examination survey is an exercise in achieving a proper balance between the goals and the constraints. The goals are, of course, the substantive purposes of the survey, and the data needed to meet the specific purposes those data are intended to serve. The constraints are manifold. First of all, they include the resources that can be made available for the survey—financial resources, personnel resources, and technological resources (including both equipment and adequate 'state of the art' measurement methodologies which will produce valid data and which are readily reproducible). All of these elements interplay in the planning process. The goal of determining the prevalence level of a specific disease, for example, can be met only if the resources permit an appropriate sample size to detect diseases at about the prevalence level which is anticipated for it; if available personnel are competent to perform whatever tests or observations are required for its diagnosis; and if the methodologies for such tests and examinations are well-established and feasible. There are still other constraints to be considered. Time factors are important. It may be a requirement that the data from the survey be made available by a certain time for some specific need, and this will greatly influence the entire plan. Time factors enter into the planning in another sense, since the total time required for each examination will be a factor in the willingness of individuals to participate. This consideration of maximizing the willingness of persons to cooperate also enters into the planning of specific content items, since one must be concerned with whether a particular examination, test, or procedure is likely to be generally acceptable.

Early in the planning phase, it is desirable to specify, in whatever detail is possible, the first approximation of the substantive purposes of the survey and of the known constraints. These broad guidelines will be developed in more detail as the planning proceeds. The first statement of guidelines is likely to indicate the decisions made as to whether the survey is to be 'cross-sectional' or 'longitudinal' in nature. For national health examination surveys, the cross-sectional type is likely to be preferred. In this, a sample of the population to be studied is selected independently for each successive survey. In contrast, for longitudinal surveys, one selects a sample and then regards this sample as a cohort to be studied in successive surveys. While for certain purposes the cohort study has clear advantages, for example, measurement of 'growth spurt' in child development, (Tanner 1962), there are many new problems in such a survey. They include follow-up difficulties aggravated by population mobility, and biasing effect of the preceding survey on the findings in a succeeding one.

Another decision to be made early in the planning process is whether the examination is to be strictly a single-visit one, with all the sample receiving an identical set of tests and procedures; or whether it may include some limited short-term follow-up visits for additional tests, with such visits dependent upon results of the earlier uniform screening test. Here again, the decision must depend upon the specific purposes involved, as well as on other factors, but in general it is desirable to aim for a single-visit examination which will obtain at that one time all of the examination data desired. The necessity for a follow-up adds greatly to the complications of operations. It also introduces an additional possibility of non-response which complicates the analysis. In some instances, however, it may be desirable to obtain information which requires testing to be carried out on two different occasions, and this may be feasible if not on too large a scale.

Sample design

When some of the general guidelines for planning the survey have been established, incorporating many of the basic decisions, work can begin on the sample design. This process must be carried out concurrently with planning the content of the examination, and the logistics to be employed in the operation, since all three factors interact. It is essential that the survey be based upon a defined and known population, and that the examined persons be a probability sample of that population. Random sampling, the special case of probability sampling where every member of the universe has a known and equal non-zero probability of selection, need not necessarily be used if there are sound reasons for differential sampling. The population and the probability of selection therefrom must be known, however, and this probability, of course, must be greater than zero. The general principles that govern sound design of statistical samples are applicable to health examination surveys, but the relatively high cost of data collection usually requires much smaller samples than in some other surveys, and this affects sample design. It may lead to more intensive stratification in the sample selection process, in order to ensure inclusion in the sample of adequate numbers in particular sub-groups of interest. The operational requirements of health examination surveys set sharp limits on the number of separate locations at which it is economically feasible to operate; hence there may be a highly clustered sample. The size of sample required for a survey is influenced by a number of factors. These include the sample design, estimating procedure, confidence-tolerance specifications, variability and prevalence of population characteristics to be measured, available budget and unit costs, and operational constraints placed on the design. Once all such factors are determined, and therefore fixed, the sample-size requirement for a stratified design will vary depending on how the sample is allocated to strata and how the sample is clustered within strata. The subject of sample design in a particular health examination survey is treated more fully in a NCHS report (2/43).

Survey design

Concurrent with the tentative decision to include an element in the examination (some specific disease problem, for example), there are a number of other activities which must be carried out. In all cases, the required forms must be developed, and this includes not only forms on which the examiner will enter findings but related medical history forms, questionnaires designed to obtain required associated data and classificatory information such as demographic data, information on health behaviour patterns, and other pertinent matters. Sometimes methodological studies may be necessary in order to adapt existing measuring instruments to the survey situation. Always there must be pilot studies and tests of elements of the survey plan, some of them separately and then all of them together. In all of this there must be consideration of how the operational and logistical problems involved in a national health examination survey will impact upon the programme and upon the quality of the data. The process of planning should produce a quality control programme to govern the subsequent data collection operation.

15.6. Data collection and monitoring

As has been indicated, the method of operation for the conduct of the examinations, the data collection process, has to be taken into account in the planning process. Concern with the operational aspect of health examination surveys is obviously not limited to planning, and it is so important that it demands considerable attention. These surveys share most of the operational features of interview surveys and health record surveys, since they may well actually include obtaining data by histories, interviews, questionnaires, and checks of medical records. They have, however, many other operational aspects which are peculiar to this type of survey.

In any sample survey there is the question of sampling error, but if the sample is properly designed and executed, one has a measure of this error and it can be controlled from the start. The other class of error, non-sampling error, is of more concern. This class includes conceptual errors, such as problems in definition or survey design, and errors in processing and analysis, for example, incorrect coding or faulty interpretation. There are two other subclasses of non-sampling error that are related to the data collection process, and they are especially troublesome in health examination surveys. These are non-response errors and measurement process errors (National Center for Health Statistics 2/44). They demand attention throughout the data collection process, but they may also have a major influence upon the operational mode selected for the survey. Theoretically, the type of operation might be decentralized or highly centralized as to control. It might involve use of many different and already existing facilities, or it may involve the use of a few specially designed, mobile examination centres. The staff may include professionals, paraprofessionals, or operators at various levels of skill. In the USA, the NCHS has so far taken the position that it is necessary to have the examining done by highly skilled examiner teams, trained and directed by Center staff, working in the standardized setting of a mobile examination centre, because of concern with the possible errors which can be introduced either by non-response or in the measurement process. Errors of these kinds are found in all surveys, but because of the nature of the data collection process they pose unusually difficult problems in health examination surveys. That portion of measurement error which is random (not due to bias) also poses unusual problems because of the necessarily smaller size related to the high per unit costs.

Non-response error

Sound sample design is a necessary but not a sufficient condition to permit generalization about the universe sampled in any survey. One must also obtain data from an acceptably high proportion of the selected sample persons. In any voluntary sample survey it must be anticipated that it will not be possible to obtain the desired data for all members of the sample. In a health examination survey the extent of cooperation required of the sample is especially great. It involves direct physical examinations, tests, and procedures carried out by examiners who do not usually provide that individual with medical care, and at a time when the individual may feel no need for the examination. In contrast to household interviews and questionnaires, it involves the additional time and effort of going to a designated place to receive this examination. All of these factors, when the participation is entirely voluntary, present the danger that a large part of the selected sample may not participate. It is not possible to avoid this problem by adjusting sampling weights to correct for non-response nor by substituting other persons, since to do so would bias the sample. It is of great importance then to make considerable effort to obtain cooperation from a high percentage of the sample.

There are a number of steps that can be taken to maximize cooperation and so to minimize non-response error; one such is to avoid unnecessary increases in the burden involved in cooperation. One way in which this can be done is by offering to schedule the examination at a convenient time, and at a reasonably convenient location; and it will produce better response rates if arrangements are made to transport individuals to the site of the examination. It should be possible to assure persons that the examination will not be painful and will not involve any significant risks to health. This means that all appropriate protective measures and precautions must be taken to avoid any hazardous procedures, taking into account any special conditions in individual cases which might increase the risk. There are various ways in which the sample benefits from participation in a health examination survey, and it will help in obtaining the required cooperation if they are made aware of these benefits. The findings of the survey examination on a particular individual may be made available, with his consent, to the physician who provides his usual medical care. Thus, without cost, he has the benefit of a battery of tests and procedures which may reassure him as to his health, or in the event he has certain health problems, may alert his physician to them. There are other kinds of benefits. The individual may be made aware of the survey's benefit to him as a part of the broader society, in which we all benefit by increased health knowledge. There may be prestige benefits or curiosity-satisfaction benefits which can be adduced to gain cooperation. The foregoing and other similar somewhat intangible benefits should be taken advantage of in maximizing response. Finally, it may be necessary to add some tangible reward for participation. In the current programme a set money payment is made as partial recompense for the time and effort involved in participation in the survey.

The effort to minimize non-response is aided by steps which make the potential respondents aware of the legitimacy and the scientific nature of the survey programme. Sponsorship by a Federal health agency is usually a favourable factor, although with some individuals the reverse may be true. Awareness of the programme, and a generally favourable attitude, towards it on the part of the medical profession, both nationally and in each area, are helpful factors. Sometimes it is useful to have news items in the press or other media which describe the nature of the programme. Newspaper items may not have come to the attention of sample persons, but when the interviewer can show clippings from local papers some assurance of legitimacy is obtained. Always there should be carefully prepared information leaflets which present the programme in easily understood terms. It is important to make the potential respondent aware that the data are being obtained for statistical purposes only and will be held confidential and not used for other purposes such as, for example, eligibility for benefits under some health programme.

The most important factor in obtaining acceptable response rates is probably in the interviewing process by which the individual's consent to participate is obtained. This process must be one which utilizes a skilled and carefully trained interviewer and permits him or, more frequently, her, to be flexible in the approach taken with each person. Individuals vary widely in their motivations, and the very thing that will persuade one person to participate in the programme may contribute to another's unwillingness. The interviewer's art consists of sensing the approach that will be successful. It may be advantageous if the effort to elicit cooperation is a two-stage procedure. A less highly-trained interviewer would conduct the first phase and would obtain the consent of those—probably a majority of the persons who proved to be readily cooperative. In all instances where there was a problem encountered or suspected, this interviewer would not pursue the question of consent to participating. A more specially skilled interviewer would make a subsequent visit to such individuals, and the success of that visit might be enhanced if the earlier effort had not been pressed to the point of a definite refusal. The degree of success in obtaining cooperation in a health examination survey is a function of the kind, and amount, of effort that one makes towards this end. Initial reluctance to participate does not necessarily mean definite unwillingness. It may be that with a better understanding of what is involved willing cooperation can be obtained. In this effort it is important to make a careful and intelligent assessment of all factors that may be involved in the reluctance, not just the stated reasons. Age and personality of the interviewer vis-à-vis that of the sample person, for example, are among the various considerations of which one should be aware. Above all, the motivation of the interviewer has considerable effect on the motivation produced in the sample person. More detail on factors related to response in a health examination survey can be obtained from the NCHS report (2/36).

Measurement process error

The other category of non-sampling error, measurement process error, is at least as important as non-response error. There are problems of measurement error that are unique or especially pertinent to health examination surveys, although the kinds of measurement process error found in, for example, health interview surveys, are also applicable to interview elements of examination programmes.

Many of the measurements obtained in a health examination survey may be markedly affected by the immediate environment in which the measurement procedure is conducted: results of a test of hearing are obviously affected by ambient noise levels; visual acuity tests require standard illumination; more complicated measurements such as spirometry or exercise tolerance tests may be affected by both the temperature and the humidity in the testing area; and other examples could be given. The important principle is that effort must be made to ensure that the measurement process is carried out in a standardized environment whenever environment affects the measurements. Just what the environment is may be less important than that it be the same for all examinations, since differences observed among sub-groups of the population need to be analysed without the possibility that they may simply reflect differences in test environments. Even more important than a standardized environment for test administration or procedure performance are the two matters of the measurements themselves, and the way in which they are made. This does not refer to sensitivity and specificity of the tests or measurements; both are important but both should have been considered in the planning process when the tests were selected. With respect to measurement error, the question is one of standardization, reliability, or repeatability. There are a variety of ways in which measurement error can be introduced. Some of them are common to all types of health surveys–omission of an item or incorrect recording of an entry, for example–while others are peculiar to, or especially likely in health examination surveys. In this category are a multitude of different possible errors in technique, a set for almost every test or procedure; one example is imprecise selection of the location in which a particular skinfold measurement is to be taken. Frequently use of instruments requires reading a value which is then recorded and there can be error introduced through imprecise or inaccurate reading. To give one more type of measurement error, very many tests or measurements require a considerable degree of active cooperation on the part of the subject. The examiner must obtain this or the survey result will not be a reliable measurement. An example of this is the necessity that the subject maintain an erect and perpendicular position when height is being measured. Another example is the kind of test which requires maximal effort, such as spirometry or exercise tolerance tests. Results of such tests and numerous others are highly dependent upon obtaining full cooperation from the examinee.

Having selected a test or measurement process which is not only sufficiently specific and sensitive but also susceptible to standardization, it is necessary to take several steps to ensure the reliability of the data. These include selection of appropriate examining personnel, written manuals of instruction specifying in exact detail how the measurement is to be made, training of the examiners, and process control measures which will detect drifts in technique with retraining as required. Still another way of coping with some types of measurement error is the use of devices which reduce the likelihood of a particular kind of error. For example, a weight scale which automatically prints the weight onto the examinee's record reduces the likelihood of recording errors. In the US surveys, stature is recorded by use of an instrument which photographs the scale value so as to avoid possible reading errors due to parallax in the examiner's observation of the height value. In measuring exercise tolerance, a specially developed elevating treadmill is used which is driven at a determined speed and thus requires the subject to walk up a set grade at a set speed. However, there is danger in the use of elaborate instrumentation, since any measuring instruments may come to be faulty. If they are complicated, both the likelihood of this and the difficulty of detecting it may be increased. It is essential in all aspects of the measuring process that measuring instruments be recalibrated regularly and frequently. It must be reiterated that this applies to simple as well as to complex measuring instruments. The rod of an anthropometer, for example, can come to be slightly bent out of line, and the subsequent measurements will have a systematic bias in them. Repeated and adequate calibration measures for every instrument must be a part of a health examination survey.

Quality control

The preceding paragraphs concerning measurement error, although somewhat general and necessarily brief and incomplete, should nevertheless serve to indicate that a thorough quality control programme is an important part of any health examination survey. In such a programme, replication of measurements can play an important role. The desirability of using this technique in the interpretation of X-rays (and other 'hard documents') has been well known since Yerushalmy's early work more than 25 years ago (Yerushalmy 1947). Health examination survey experience in the USA has shown that the method could be used even on parts of the clinical-type examination which produced no 'hard document'. For example, although some difficulty in subject participation was encountered in repeating the entire examination, it was still possible with only moderate effort to re-examine 70 per cent of the sub-sample of persons chosen for complete replicate examination in one survey. Moreover, when only portions of the examination were repeated independently by a separate examiner during the same visit, there was no objection to repetition of such elements of the examination as the dentist's assessment of oral hygiene or the ophthalmologist's findings of diseases of the eye, even though the repetition was solely for quality control purposes, and the subject had been so informed. Such procedures, done on samples of examinations, provide objective measures of the reliability of the examination findings.

One final point should be made concerning all of the measures adopted as part of the quality control programme in a health examination survey. There should be early evaluation and feedback from the parts of the programme that detect any measurement errors so the necessary corrective actions can be taken. It might be contended that this use of data from the quality control programme would lessen another usefulness of these same data on extent of errors detected—namely, their use as a measure of the reliability of the total survey operation. Since intervention on the basis of errors found should affect the rate of error, the per cent error rate will have been modified. The importance of correcting the examining process is, however, overriding.

15.7. Data processing and analysis

Once again consideration of the methodology in data processing and analysis is limited to a few remarks on aspects of these problems that are particularly relevant in the health examination survey setting. The nature of such programmes, wherein every member of a sample of the population undergoes a considerable number of different tests and procedures related to a variety of health conditions, leads to desires that the resultant data analysis should consider many known or suspected relationships among the various findings. This fact, along with the volume problems involved, means that it is desirable and sometimes essential to use modern computer methodologies in the data processing and analysis steps. For example, in the processing of nutrition data concerning dietary intake in the Health and Nutrition Examination Survey, the very large number of different food items, each of which has associated values for a variety of specific nutrients, require complex computer programmes. The data processing operations such as editing and later tabulations for analysis require large numbers of manhours and access to fairly large computers.

There are many parts of the data preparation and processing in a health examination survey which require special attention and particular skills. Much of what is collected in the examination requires additional operations before one has data susceptible to computer processing: X-rays, electrocardiographic tracings, spirometry test results, urine, blood, or serum specimens, are examples of this class of data. Whether one regards all of the steps involved as being part of the data processing or the data collection, the fact remains that they all do present special problems requiring skilled attention. Concern with measurement error will, of course, extend to these operations of reading; the process of handling laboratory specimens, including preparation, shipping, and storage; laboratory testing, interpretation, and the like. At every point in the chain of processing it is essential that quality control measures guard against possible events which could affect the basic data.

Special considerations of sample design already mentioned necessitate some new methodologies in the analysis process. An example is the problem presented when variances are to be computed for data collected in a complex survey design involving such deviations from simple random sampling as multistage samples with high degrees of clustering. In the US survey this particular problem has led to investigations of replication methods which are dependent upon some new theory and heavily dependent upon computer technology. These methods have been documented in the methodological reports subseries in the series of Vital and Health Statistics Reports (National Center for Health Statistics 2/14, 2/31, 2/65).

15.8. Health examination survey programmes and problems

Thus far, this paper has attempted to present general principles which may have applicability in any health examination survey undertaking. Of course, to a considerable extent, these have been distilled from the experience of the health examination surveys in the USA. It therefore seems appropriate to give a brief history of activities in this areas. There are available published programme descriptions which give considerable detail concerning the specifics of each of the programmes (National Center for Health Statistics 1/4, 1/5, 1/8, 1/10). Such details cannot be given here, but an abbreviated description of our surveys and a few specific instances of problems encountered, including ones dealt with satisfactorily at the appropriate time, and others which proved more troublesome is relevant.

The first health examination survey programme (sometimes referred to as the 'first cycle' to denote the concept of an ongoing series of examination survey programmes) had as its target population the US adult population between the ages of 18 and 79 years. The target conditions of the survey included the various specific forms of heart disease (hypertensive, coronary, rheumatic, and so on); the arthritides (rheumatic arthritis and osteoarthritis); specific dental conditions; and measurement data with respect to visual acuity, auditory acuity, blood pressure levels, height, weight, and other measurements. The sample consisted of about 8 000 adults, and the programme succeeded in examining more than 85 per cent of the sample. The examinations were conducted in specially designed tractor-drawn trailers which, when parked alongside one another had connecting passageways which made a small mobile examination centre. More than thirty reports have been published presenting the findings of this programme. The pattern followed in presenting the data has been to put data on each particular topic, such as blood pressure levels, or osteoarthritis prevalence, in a separate report. This has been done for two principal reasons: (i) to permit somewhat earlier release of some of the data, and (ii) in recognition of the fact that the users of health examination survey data are highly varied and specialized, and many of them are interested in certain findings but not in others.

The second and third health examination survey programmes were closely related in that both were primarily focused on factors related to growth and development. The second had as its target population children at ages 6 through 11 years; the third youth aged 12 through 17 years. Elaborate sets of anthropometric data were collected with the purpose of replacing outdated and non-representative normative data that have been widely used both in the USA and elsewhere. A psychometric battery was included to obtain some data relevant to intellectual and emotional growth and development. Because chronic disease prevalence rates in these ages are too low for detection by this survey mechanism, the problems of ill-health included in the target conditions were largely limited to dental conditions and sensory defects (visual and auditory acuity problems). Of course, the measurements obtained provided normative data in these areas as well. The sample size in each of these programmes was about 8 000 persons. More than 96 per cent of the children and over 90 per cent of the youth selected for the samples were examined. Reports on most of the findings have already been published, and work continues on analysis of some of these data.

The fourth health examination survey programme was originally planned as an effort to obtain some prevalence data on certain chronic diseases in the adult population together with an assessment of the unmet medical care needs of that population. This plan was expanded when the Center was assigned a new responsibility for measuring and then monitoring the nutritional status of the total US population. A combined Health and Nutrition Examination Survey (referred to as the HANES programme) was the result. All members of its 28 000-person sample, aged 1 through 74 years, were to receive an examination related to nutrition; while a sub-sample in the 25-74 year age range were to also receive the more detailed health examination including the assessment of unmet needs. The data collection phase of this first HANES programme has been completed as far as the nutrition examination is concerned. Because of the small size of the sub-sample for the more detailed health examination, it was planned to examine an additional separately selected national sample, and this is the programme now under way. Meanwhile, nutrition data from the first HANES programme are being tabulated and analysed. Two preliminary reports have been published (National Center for Health Statistics 1974*a* and 1975), and the first reports on the full nutrition sample will be completed later this year.

Many of the problems encountered in the health examination surveys have been in the area of quality control. They have included personnel failures, equipment failures, failures in specifications of technique, and failures in standardization training, to list but some of the categories. To illustrate the first type, there have been instances of lost data because of improper specimen shipment or record handling. Equipment failures have included instances where machine malfunction was not detected promptly with resultant introduction of measurement error or sometimes complete loss of data. The technique specified for handling of blood serum specimens at one point was too imprecise, and different individual interpretations of what quantity of ascorbic acid was to be added as a preservative to the tube of serum for folate determinations—the specifications called for 'a pinch'—led to distortion of the subsequent laboratory values of folate levels. And failure to train technicians in the performance of various measurements of range of motion of joints reached the point where the resultant goniometry data did not have an acceptable degree of reproducibility. These are listed out of many problems to make the point that anything can go wrong, and one must be constantly alert to guard against measurement error and then to detect it when one fails, as is sure to happen in some instances.

Another kind of problem faced relates to the size of the sample, and concerns the growing need for data that are relatable to much smaller geographic and political areas than national or broad regional data. This problem is not yet solved but work on perfecting methodology to obtain improved estimates for local areas from national data continues. This would involve identifying a large set of demographic and social data which are correlated with the desired survey findings and which would be known or obtainable from other sources, such as the census.

The problem of obtaining completely satisfactory response levels is one which still requires solution, although some success relative to other national or major nutrition surveys can be reported. The adoption of the practice of giving a money payment to each sample person who completed the examination referred to earlier seems to have helped, but the problem is one which must be addressed constantly. The 75 per cent response in the first HANES programme is lower than had been hoped, and several research studies related to this problem are being undertaken. One is concerned with the possible biasing effects of the levels of non-response experienced. It is not yet complete, but there are some indications that the kinds of objective observations made in an examination survey may be less biased by a particular level of non-response than are the more subjective interview type of data. It seems reasonable that response behaviour would be little affected by physiological measurements, and health states of which the individual may be totally unaware. While research on the general topic continues, everything is being done to improve response rates.

Let me note one final problem, by no means the only other one met, but one last example. There is no possibility, with the limited dollar and personnel resources, and time available, of being able to fully exploit the extensive sets of data which have been and are being collected. Some of the basic findings for each of the different items are presented; together with differences by age and sex and differentials by various other demographic and socio-economic variables; but that is only a part of what can be done. In addition, the new research and analysis programmes within the NCHS are beginning to produce some epidemiological analyses of these data. One benefit, of course, is that shortcomings in the data, identified in such analyses, can lead to design changes in the next survey. There are, however, very many other interrelationships which need to be explored and very many kinds of more intensive analyses to which the data should be subjected. To attempt to address this problem, survey data is included in a Center-wide programme by which basic data tapes are made available at a nominal charge for the use of outside scientists and researchers--in government or private agencies. (National Center for Health Statistics 1974*b*). These tapes are, of course, stripped of information which would permit identification of any individual, but they present all the other basic data for each of the persons examined. This makes it possible for other persons to complete, or at least to progress further, on the work which has only been begun.

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Paper 16

General survey systems or *ad hoc* enquiries?

A.S. Härö

16.1. Summary

This paper considers the roles of HISs and reviews the concepts of 'systems', 'management', and 'planning'. It discusses the decision-simulation approach to deciding the scope of the information required from an HIS, and the problems of detailed information versus national statistics. It goes on to compare the respective merits of continuous and *ad hoc* surveys, and the contributions of automated information systems and data banks. The paper emphasizes that the level of data provision must be controlled by the needs of the users of the information and the state of technology; and that there is tremendous scope and need for the proper planning of health information systems.

16.2. Introduction

> *'There is no wealth equal to knowledge, and no poverty equal to ignorance, and no support equal to sound advice'.* (Said by the 4th Kalifa, Sayad Ali Ibn Abe Talab).

Health surveys are primarily designed to produce information on the health, and related factors, of a population, delineated on the basis of criteria such as age, locality, or occupation; but in the context of this conference interest should be focused on national surveys, or comparable activities. Surveys designed to test research hypotheses are outside consideration; these tend to concentrate on problems of scientific exactness and methodological innovation, although they can also be useful adjuncts to national systems. It is also obvious that the information from surveys is intended to form the basis for logical decisions. In many, or probably most, cases there is no one identifiable decision maker and information is produced to aid anyone who, formally or informally, is involved in the decision-making process.

It is most unlikely that all the information needs of decision makers will be met, especially if the term is defined so broadly, and therefore some kind of picture or 'model' of alternatives, which should be considered in relation to the problems is also needed. The word 'model' here does not imply a quantitative or mathematical one, but simply a comprehensive list of relevant points or questions to be answered before decisions can be formulated. Such models can be produced only by experts in various fields who thoroughly understand the problem.

This paper is basically concerned not with the content, but more with the methodological aspects of information. However, it must be stressed that methodological questions should not be considered in isolation, but as part of the decision-making process as a whole. This is especially true, when 'strategic' problems—a continuous versus an *ad hoc* approach, for instance—are under consideration. The use to which the information is to be put should, in the long run, determine which is the correct strategy, taking into account the known merits and limitations of different approaches.

More generally it can be said that the problem is to plan health surveys as a component of an HIS, in such a way that the cost/benefit ratio of the system as a whole is acceptable.

16.3. Some definitions

The word 'system' is mentioned in the title and in the previous section. It is very relevant to the discussion; however, if not explained it could be misunderstood. System in this context does not mean entirely organized, methodical, hierarchial, but

> *a group of components working together for a purpose.*

The components can be *concepts* (such as health), *ideas* (such as equality), *objects* such as hospitals), *persons* (such as physicians) and so on. Together these form a 'whole' in which the components interact, either supporting or controlling each other. The element that makes interaction possible is information–in its widest possible meaning. The components of the system are themselves systems (sub-systems) and any system is a part of a greater one, or more usually of several greater ones.

The previous statements are truisms, but the systems concept has proved to be a useful framework not only for theoretical considerations (Ackoff 1974, 1971) but also in practical operations. A very promising area is the application of the systems concept in management.

> *Management is the function of guiding the system as a whole in a planned direction.*

Modern or 'scientific' management which operates a system with the whole in mind is called *systems management* or *management by systems* (Johnson, Kast, and Rosenzweig 1973). Its real strength is in complex situations where systems approach can foster a way of thinking which focuses attention onto the real goals of the activity. One of the most difficult management problems is to balance efficiency and effectiveness especially when, as frequently happens in the health field, the two are in conflict. Often one sector is undeniably efficient, but consumes resources which, if used differently, could markedly increase more valuable output in another sector. A well-known example is the situation in which resources are tied to sophisticated curative services, and too few are left for preventive medicine–more vital for the effectiveness of health service activities as a whole (World Health Organization 1966).

Management can also be seen as a system itself, partly formal (administration), partly informal (pressure groups). Its main product is instructions to sub-systems to order their behaviour. The essential element in management is decision making, and the decisions, based on information of different kinds, actually appear as instructions.

> *Information system is the generic term for all activities which ensure that management has the relevant information when making decisions.*

It is erroneous to think that only measures of quantity and quality are involved. In reality management also bases decisions on value judgements, intuitive predictions, and past subjective experiences. It is hardly necessary to add that in practice the information production system is delineated more narrowly. But the term 'information system' in this paper does not merely mean statistics. In principle

> *a Health Information System incorporates all possible methods or 'channels' which can produce answers to questions posed by the decision makers.*

The routine statistics, different kinds of registers and reliable opinions are components of the information sub-system; but it also includes published information on other relevant situations, and of course the results of surveys and research of various types. All these have their merits and limitations, and the problem to be solved dictates which is the most useful (Härö 1972).

16.4. Planning of information production

Information can serve various purposes in any organization but one of its main uses is in planning (World Health Organization 1971). Again the word planning has different meanings. Generally speaking all decisions require some preliminary consideration which can be labelled as planning, but more formalized use of plans in administration requires a more formal planning process.

> *In each organization the decision making is a unique process and the planning is accordingly different.*

There are, however, numerous principles which are valid in all circumstances. This is especially true if the objective is to plan information services or the production of information.

Planning an information system, which, as stated, should primarily serve the decision-making and management processes in a system, has technical and scientific aspects. But in principle the correct planners are those who will use the information; and this also holds true for the planning of health surveys. The statisticians, epidemiological researchers, and numerous other experts all have something to add, but they are not the sole self-evident planners.

The preceding discussions stress at least implicitly the difficulty in knowing what should be known. A prerequisite, at least in theory, would be a stated programme, a description of objectives, and of national goals for health services, or comparable documents. In practice such statements do not usually exist, or they are formulated in such a way that their practical value, at least for planning an HIS is limited. In most cases even the officially accepted health plans have the same weakness -a lack of definition of the ultimate goals of activities. This is understandable because people see aspects of the system in different ways, and their value judgements do not assess priorities in the same order. A national health programme can be a formal statement, but in reality more essential is that

> *the decision makers at all levels should understand and accept the programme in principle, and should have comparable 'mental models'--the same way of thinking about the goals of the organization--as a basis for their decisions.*

Those responsible for the planning of the HIS must also be able to translate the programme and/or the 'mental models' into definable inputs and outputs of resources or services.

Managerial decisions are in principle based on evaluative considerations of efficiency and effectiveness. These two ideas are based on different 'models' and require different types of information. The 'goal attainment model' is concerned with effectiveness and usually relies mainly on epidemiological studies. For practical management purposes a 'control model' which concentrates on efficiency and the correct use of resources, is at least as important. Finance, personnel, workload, and other measures which might be of little interest to an epidemiologist, are valid indicators in this model, which sees the activity as a continuous service to be controlled. These two 'models' are visualized in Figs. 17.1 and 17.2. Information for management must be reliable and relevant but these terms are not in this connection identical with scientific exactness and scientific value. There are exceptions, but very often

> *relatively crude, but in principle correct measurements at the right time are more helpful than exact results of research, available after the decision has been made.*

A well-planned HIS should provide both the crude and the more refined information.

Properly organized teamwork, in order to make the cooperation of different disciplines fruitful, is also an essential prerequisite for the planning of a good HIS. One practical solution to this difficult problem is a systems-oriented 'decision simulation approach' which has been used by NOMESKO (Nordic Medical Statistics Commission 1973) in the Scandinavian countries. The basis of the approach is to form teams, composed of decision makers, expert advisors from various disciplines, and information specialists, to analyse a suitable sector of services (tuberculosis, or dental health, for example), and to try to simulate the decisions which are being or should be made in the sector. The aim has not been the formulation of plans, but agreement on the information items or indicators needed *if* anyone is to make decisions on problems in the sector. The simulation exercise can be conducted in a way which will allow constructive discussion of different alternatives, without undue criticism by any one discipline. Questions such as: What should be known? With what precision? How frequently? Presented in what manner? can usually be answered logically. The leading role has been given to the decision makers and as a result

> *the decision-simulation team can form a picture of relevant 'mental models', indicate which are the critical decisions needing 'tailor made' information, and which information is less useful.*

The approach can be used at any level but is especially suited to national problems and programmes. The role of information specialists is to plan the services in a technical sense and to ensure that the information produced, notably statistics, is suitable for other valid purposes, for example, for international comparisons. The simulation of decisions is not anything revolutionary; it conceptualizes and guides a process which, usually carried out in some form when an HIS is planned, tries to draw attention to the common misconception that a straight question 'What kind of information do you need?' can easily be answered, even by responsible decision makers.

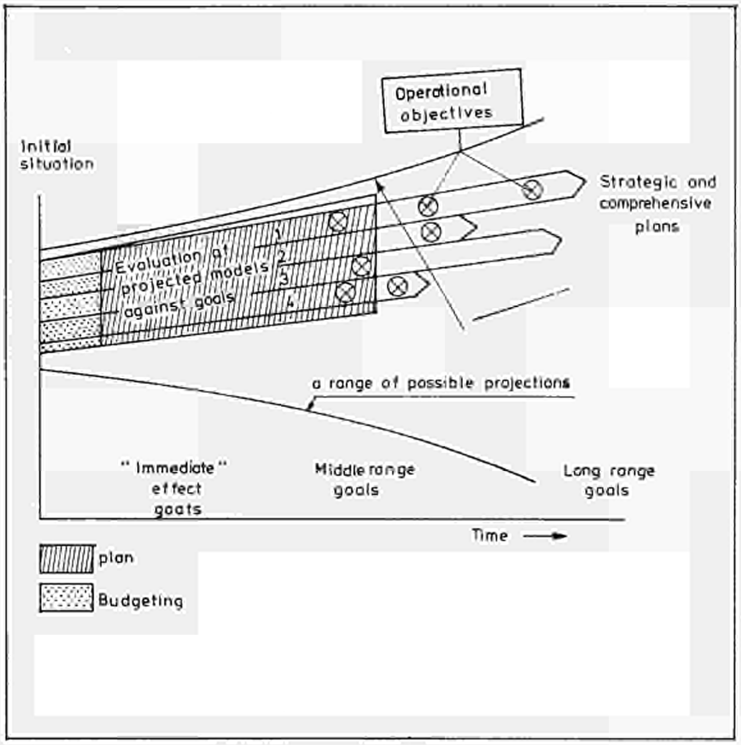

FIG. 16.1 *A planning framework for social policies.*

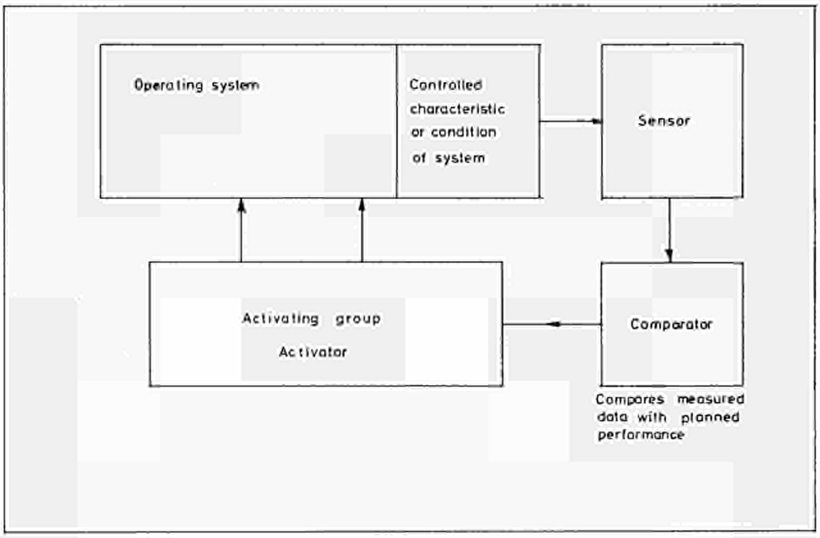

FIG. 16.2 *The elements of a control system.*

16.5. Technical aspects of surveys

The basic element of the traditional statistical system–'routine statistics'–is a questionnaire or form which summarizes work done, normally over a definite period of time. These summaries are usually processed into statistics at a medium administrative level, and then aggregated to give the national figures. Thus the classical 'power pyramid' has its counterpart in an information pyramid, which means that the information available to society reflects only those topics in which administrators were interested when the basic forms were designed. Such an information system has some positive aspects; the system is cheap or seems to be cheap, does not require very much expertise and usually produces long time-series. On the other hand, the system is rigid and often cannot answer newly formulated questions, and a great deal of information is lost when the basic data are aggregated. The rigidity and the small amount of relevant data limit the value of the system, especially for planning and 'scientific' management although there are some requirements for information which such a system meets quite well. An additional problem is that the first step in the system cannot be automated; the basic forms must be completed manually.

The mechanization and automation of data processing has made feasible statistical systems which are quite different in principle. In data archives (registers, databanks), the idea is to store the individual (case/event level) data, rather than the aggregated statistics, and to organize the data processing so that the information content as a whole can be regrouped to provide any tabulation or representation. Thus, if technical difficulties can be overcome, the problems of rigidity and loss of information can be eliminated. The source of information varies but in essence

> *Surveys are 'technically speaking' data archives (registers, databanks) in which facts concerning an individual person, patient, event, case, and so on, are deposited.*

Some of the advantages of data archives have been mentioned, but again there are also limitations. Such sub-systems require much expertise, both in their planning and their actual conduct since, in spite of their relative flexibility, the usefulness of the data is limited if the basic measurements are not relevant or reliable. In theory it is possible to construct 'all-comprehensive' databanks, which cover broad problem areas, but in practice it is more profitable to have specific registers located in strategic positions, so that they cover areas for decisions or research. Small databanks can be managed manually, but the systems are usually based on electronic data processing methods. Another important factor is the integration or linkage of several registers which can be achieved by systematically using the same classifications, definitions and codes. A personal identification number is very useful in this respect but for practical purposes numerous other 'integration keys' are satisfactory. It is scarcely necessary to mention that the more comprehensive the register, the more complicated the codes. Undeniably the routine statistics can be considered as data banks of aggregated data from service units, administrative areas, and so on.

16.6. Merits of the *ad hoc* approach

Specially planned *ad hoc* surveys in which the basic measurements are selected and processed to answer exactly formulated questions are a necessary and traditional method in any organization and their merits are too well-known to require further discussion. But in the context of this Workshop Conference, the focus of interest is surveys in which numerous data concerning an individual person or event are collected and later analysed. There are very different types of health-related surveys but possibly their greatest advantage is that data can be collected across the sectoral boundaries of societal systems, and diverse information on an individual respondent (or event) can be linked to their health status, for example, different factors concerning past and present environment, both physical and social. The same range of information collected from a variety of sources would require a very advanced and well-organized information system. Currently the linkage of data on the basis of a personal identification number or corresponding method is a utopian dream. Another point worth mentioning is that *ad hoc* surveys rely less on the organizational infrastructure than do, for instance, routine statistics. There are, of course, some technical difficulties, although these are relatively minor. There is frequently a long delay between the completion of the data collection and the publication of the results. Surveys require a high level of planning and analytic skills and it is not too common to find staff with suitable expertise waiting for opportunities to use these skills. Another difficulty is the relatively great short-term costs which sometimes do not fit into the framework of administrative routines.

A single *ad hoc* survey is a situational analysis of present circumstances. A well-formulated basic questionnaire or form can allow conclusions to be drawn about trends, which in most decisions are more important than the results alone. One possible solution to this limitation is to repeat the survey. Various factors dictate whether the same population can be used, or whether a new sample must be selected. A before/after strategy can be useful in a situation where new legislation, a major innovation, marked increase of resources or some other unique event can serve as a dividing line. In some cases the trends and influences of continuous step-wise progress can be measured by repeated surveys based on comparable sampling frames; a good example of this is a periodic unemployment survey.

16.7. Merits of continuous surveys

The continuously repeated survey comes, at least in principle, very close to a register, which records events continuously. Registers are very suitable when the decision makers require information to feed into a 'control model'; the relevant indicators are well-established, and interest is limited to one or a few societal sectors. A typical situation is when interest is focused on the users of a service unit as with, for example, hospital discharge reporting systems, based on individual patient summaries. The length of stay is long enough for it to be reasonable to require relatively detailed information on the diagnosis, treatment, and so on. This is much more difficult to do in situations where the contact is very short, in out-patient clinics or dispensaries, for instance.It may be possible to collect detailed data on a sample of the total, but even this is in most cases difficult.

A continuous survey which requires a special organization of interviewers or measurement experts is a very expensive instrument especially when the whole population must be covered. It is presumably justifiable in circumstances where the organizational resources vary markedly and unsystematically in different localities; when the size of the population would make other approaches still more complicated; or when well-defined needs for information are so critical that great investments are reasonable.

Continuous registration systems increase markedly the capacity to analyse trends and the effects of sudden changes. They also facilitate the evaluation of past decisions and form a useful database for health and social policy decisions.

16.8. Conclusions

Health information services form a system composed from widely differing components, and using a variety of methods. There may occasionally be technical constraints, but the strategy to be applied to a particular problem must usually be based on a careful analysis of the information needs of the decision makers--provided that these do not conflict with any goals or policies of the organization as a whole. The degree of accuracy required for the information, and the time available for collecting it, usually indicate which method would be most suitable. In general, continuous surveys are useful where decisions are based on controlling service activities, but *ad hoc* surveys are frequently necessary to provide measures of outcome to which stated objectives can be compared. In health and welfare activities, both control and goal attainment are relevant, and the two methods may well be used in parallel. It should be pointed out that survey techniques are not the only methods available.

The development of an information system is in practice closely tied to the technical achievements of data processing and the progress in this field is continuing with remarkable speed. In planning information systems, objectives which are near utopian for today will be realistic or even old-fashioned in 1985-1990, and these years are reasonable targets for present planning activities. At present many older-generation top administrators direct much of their attention to 'too much information' or 'unused statistics'. To some extent this is related to the lack of statistical education, or to overvaluation of personal experience, but often it reflects the fact that *too little attention has been given to the planning of information services.* It is easy to find examples which show that a planned information system, which provides good back-up to the planning and decision making processes so that health policy decisions are moved slightly nearer to the optimum due to better information, repays all investment. There is, in my opinion, hardly any investment in the health field having a more favourable cost/benefit ratio than proper planning of information services.

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Paper 17

National Household Health Survey; its use in planning

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17.1. Summary

This paper outlines the plans for the establishment of a health interview and examination survey in Canada, but also deals with the general concept of health surveys. It describes the three major fields on which information can be obtained from surveys: health problems; risk factors; and the utilization of and attitudes towards health services. It describes briefly a method by which priority measures for health, particularly in the field of primary prevention, can be derived. This method is still in an embryonic stage; however, it does endeavour to provide a framework based on epidemiological knowledge for available health statistics, or those which could be obtained by a national survey. In addition, the notion of attributable risk (which measures the relative contribution made by a risk factor to a health problem) is introduced; and the paper continues by indicating how a national health survey could help in the specification of priority preventive measures using this method. Other possible applications of data from health surveys in planning are considered. The paper concludes with a discussion of the improvement of health statistics in general and the role which surveys can play in this.

17.2. Introduction

When this paper was first written in June 1975, the establishment of a permanent household health survey scheme in Canada had been in preparation for approximately one and a half years, following numerous discussions and proposals drawn up jointly by the Department of National Health and Welfare, and Statistics Canada—the central statistics organization. The terms of reference for the project were laid down in an internal paper of the Department of National Health and Welfare in May 1974. The proposed household survey involves two constituent elements: an *interview* and an *examination* (clinical examination and laboratory tests). Originally it was planned that a probability sample of 40 000 subjects would be interviewed by professional interviewers, and a sub-sample of 5 000 subjects would be examined. However, it was decided in early 1976 to simplify the physical examination component originally proposed. Therefore the simplified measures will be administered to a sub-sample significantly larger than 5 000, and it is planned that the combined data collection will be carried out by a team including an interviewer and a paramedical person. These activities will be carried out over a period of one year and repeated on a fresh sample group each year. The annual cost of the project is currently estimated at about $2 million. Such an outlay can only be justified if one is reasonably sure of the benefits which will result from the information collected.

On the basis of this project, this paper attempts to describe what the fundamental aim of a national health survey should be, to outline its contribution to health planning and, more especially, its contribution in determining priority preventive measures.
Within the framework of health planning, laying emphasis on preventive rather than curative measures is certainly nothing new. Among the preventive measures which have contributed and

are still contributing to the control of disease, water purification, the pasteurisation of milk, food control, and vaccination against various infectious diseases which have almost disappeared over the past few decades, can be cited as examples. However, a study of the programmes or measures currently in operation in the field of health in Canada, as in other countries, shows that almost all the resources are devoted to curative and nursing 'systems' and that very little is put into preventive measures. Various factors have contributed to this situation: for example, the urgency in cases of illness; the sub-dividing of systems which implies that the health service is concerned with little else than existing cases of illness; the prestige of the doctor in attendance; resistance from the public, for instance, in the fight against alcoholism or tobacco; and other adverse pressures such as advertising, or stress in the working environment. This paper is not concerned with the causes underlying this situation (Fagnani 1973) however, but with the lack of accurate information and/or adequately analysed information, which could be used as a basis for taking preventive action. This lack of information concerns not only basic statistics but also the lack of results from epidemiological research concerning the role and importance of numerous social variables and those factors associated with lifestyle and environment. For better or worse, funds continue to be poured into the said curative health services, whilst numerous researchers in social medicine, or epidemiologists continue to criticise the effectiveness and even to prove the ineffectiveness of certain therapeutic measures (T. McKeown 1973, personal communication; Cochrane 1972; Gellman 1971; Boudreau 1975).

This situation came under criticism recently in Canada in a paper entitled *A new perspective on the health of Canadians* (Lalonde 1974). An extract from the preface reads:

> 'It is therefore necessary for Canadians themselves to be concerned with the gravity of environmental and behavioural risks before any real progress can be made.'

In this paper special emphasis is laid on primary prevention, that is, measures intended to prevent illness arising, in relation to environment and lifestyle. The paper itself has without any doubt some points in common with the thesis of Illich (1975) on the 'expropriation of health'.

If special attention is paid to the precise content of the questionnaire for the interview component and the examination component, the *a priori* difference in the questions asked becomes obvious, as well as the significant differences in the technical and logistical aspects of data collection for the two components. However, bearing in mind that the main aim is to use the survey data for the planning of preventive measures, it is useful that the data involved should not be categorised but rather integrated within a common framework.

17.3. Information from a national health survey

Figure 17.1 indicates the three main classes of information which could be obtained by a national household health survey. This figure will be referred to throughout this section, as well as at the end of the paper.

Health problems

The term 'health problems' is used to cover the following three types of information:

Morbidity. Morbidity can be defined as the total number of physical and mental illnesses, accidents and injuries. One common consequence of illnesses and accidents, *disability*, will be measured in terms of the number of days for which the individual has been unable to carry out all or part of his normal activities (or has been confined to bed). The measurement of this disability will serve as a kind of common denominator for all morbidity problems.
Two main categories of morbidity can be distinguished: *diagnosed morbidity*, and *perceived morbidity* (Levy, Bunger, Dumenil, and Fagnani 1973). Diagnosed morbidity is that which is defined by a medical diagnosis. It can be measured from hospital statistics, surveys of doctors, or possibly from medical care insurance data (if they include a diagnosis, as in Canada), or statistics

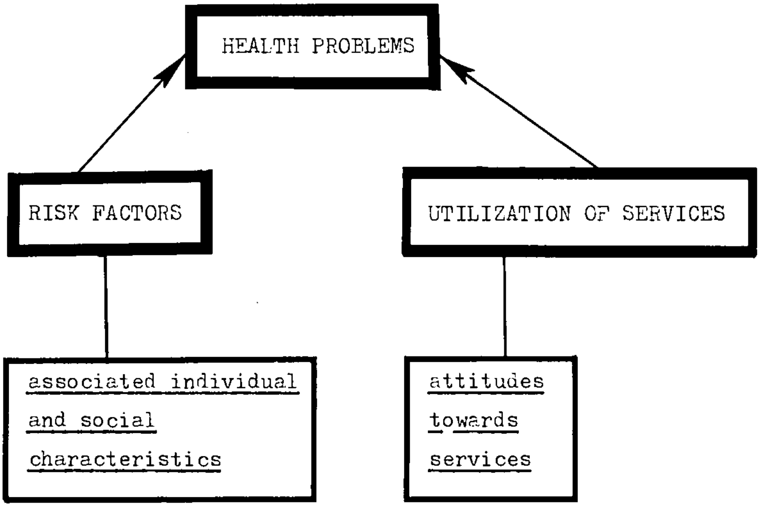

FIG. 17.1 *Diagrammatic categorization of the information which can be obtained by means of a national health survey.*

on notifiable diseases. It must be noted that the diagnosed morbidity data referred to above are obtained indirectly through health services. A national health survey would collect very few diagnosed morbidity data with the possible exception of certain cases identified in the examination component. Perceived morbidity is that morbidity which can be measured by means of an interview survey. It is often defined in terms of symptoms by the respondent, who is unaware of the exact name of the illness from which he is suffering or has suffered. Measurement of the resulting disability of various illnesses or accidents is a means of completing the diagnosed morbidity statistics by measuring one of the important consequences of the illness.

Techniques for measuring perceived morbidity have been improved over the past ten years as a result of surveys carried out in various countries. Thus in 1969 the US Health Interview Survey, after evaluating two different approaches tried out in 1967-68, decided finally in favour of the 'person approach' as opposed to the 'condition approach' used previously, which was found to discourage the confiding of information on certain conditions or health problems (Subcommittee of Statistical Methodology Committee to evaluate the National Center for Health Statistics 1972; National Center for Health Statistics 1969). The 'person approach' consists of asking each respondent whether he has been ill during the past two weeks. If the answer is yes, additional questions are put to him to determine the nature of the particular disability he has suffered. The 'person approach' is also strongly endorsed in a recent report (Mizrahi and Mizrahi 1975) on the Canadian project based on the experience of the most recent national health surveys in France. This report recommends a referencing scheme for the maximum number of health problems, based on five sections: utilization of medical services; disabilities; detailed description of the respondent's health status; medical insurances; and direct questioning on the illnesses.

Impairments and handicaps. An *impairment* can be defined as the defectiveness or loss (partial or total) of a limb, organ, or function of the human body; so that it could be the result of a congenital malformation, an illness or an accident. On a similar basis, a *handicap* will be the precise disadvantage or the nature of the activity restriction causes by an impairment or the result of a physical or mental illness (Wood and Grossiord 1974).

Each of the two components of the survey (interview and examination) can contribute greatly in assessing the significance of these often neglected health problems. Just as disability is used to measure the consequences of illness, so handicaps can be used to measure the consequences of impairments. (However, the same impairment can be a considerable handicap for one person–such as the loss of a finger for a pianist or flautist–and yet constitute hardly any handicap for another person whose normal activities are different.) Impairments and handicaps have been separated from morbidity because they are health problems for which certain specific measures must be taken. Impairments and handicaps correspond to problems which are commonly defined as chronic, as opposed to acute illnesses.

Premature mortality. This is of course the ultimate handicap; no further mention will be made of this subject since mortality statistics are a well established component of vital statistics.

Health indexes. Finally, attention is drawn to the usefulness of combining all measurement of health problems in one single indicator or index in order to classify health problems in order of importance. This is a difficult operation which will not be discussed further in this paper but its importance will again be evident in section 17.5.

Risk factors; individual and social characteristics

Any characteristic or trait of an individual or his environment (physical or social) which renders this individual more susceptible than another individual to a given health problem (mortality, physical and mental illnesses, accidents, infirmities and handicaps) is referred to as a *risk factor.* A given behaviour, such as smoking 15 or more cigarettes per day, will therefore be designated as a risk factor as soon as it has been proved that individuals who exhibit this behaviour stand a significantly higher chance than the general population of suffering from a given illness, such as lung cancer, infirmity or accident . A slightly more restrictive definition of the notion of risk factor is indicated at the end of this sub-section.

As explained in textbooks of epidemiology (Fox, Hall, and Elveback 1972; Rouquette and Schwartz 1970), the notion of risk factor should not be confused with that of causal agent. If a certain factor has been proven by several types of research to be implicated in the cause of one or several illnesses, this might justify implementing a programme of preventive measures aimed at reducing the extent to which the population is exposed to such a risk. It should be emphasized that this is an extremely delicate and controversial issue, given that the precise aetiological mechanism, or the causal chain, of the majority of serious health problems (heart disease, mental illnesses and cancer) are unknown. According to the evaluation of the role played by a risk factor, the decision could be made to implement a programme of preventive measures incorporating appropriate mechanisms of evaluation. Alternatively, it might be decided to first evaluate the effective reduction in health problems associated with a given risk factor by using an experimental group of subjects whose exposure to this factor has been reduced, if this is possible (intervention trial).

Returning to Figure 17.1, let us illustrate with the aid of an example the difference between risk factors, health problems and social problems. Alcoholism will be considered here as a risk factor and not as a health problem. Its association with various illnesses such as cirrhosis of the liver or so-called alcoholic psychoses is well known. However, it should be emphasized here that certain risk factors, and alcoholism is an excellent example, are not risk factors associated solely with health problems. Consider the alcoholic who makes life impossible for his family for as long as he is alive but has no health problem until his death at the age of 80 or 90 years. There exist, therefore, associated with certain risk factors, negative consequences which are not health related but which are related to social or economic factors. Here we have an example of how health problems and social problems overlap. The definition and measurement of social problems will not be dealt with here, but social and economic problems, resulting from certain risk factors, must be taken into account as well as the health problems when policy decisions are made.

In sections 17.5 and 17.6, an attempt is made to define a method of determining priorities for preventive action and to indicate the potential contribution of a national health survey to this process. Assuming that these priorities have been defined and that the decision has been made to implement certain measures specifically directed at certain risk factors, it becomes necessary to use additional information more detailed than the number of people exposed to a certain risk. It is at this point that the variables referred to as *associated individual and social characteristics* are brought to bear since they enable the *groups exposed to high risk* to be precisely defined.

(i) Among the individual characteristics are age, sex, marital status, education, certain aspects of family history, and various psychological measurements.

(ii) Among the social characteristics are, for example, type of work, working environment, domestic environment, rural or urban setting, and economic status (household income).

How can one differentiate between *risk factors* and *associated individual and social characteristics?* The fact is that almost all the variables listed above come within the definition of a risk factor as proposed at the beginning of this sub-section, the first and foremost being age. From the public health point of view, it would be more useful to refer only to those factors which are susceptible to modification as risk factors. Unfortunately, this refined definition is somewhat ambiguous. The age of an individual and the age structure of a given population at a given moment can hardly be modified, although the development of the age structure of a population could possibly be modified by means of demographic policies. Similarly several social and environmental characteristics, such as working conditions, should be considered as modifiable from the public health point of view. Another example of a risk factor will illustrate the notion of 'possible modification' which has been proposed to be associated with this concept. One risk factor acknowledged in various cardio-vascular illnesses is high arterial blood pressure. Pharmacological treatment constitutes one possible form of action against this (and it is important to know if the pharmacological treatment of high blood pressure effectively reduces associated health problems); on the other hand, in the absence of any treatment or form of action, simply knowing about high blood pressure would be practically useless.

Social variables play an important role in a national health survey both on the level of risk factors and that of associated characteristics. One can, however, go further in the collection of social variables by trying to measure, for example, the social isolation or integration of an individual and consider this as one aspect of his health.

Utilization of services, attitudes towards services

The utilization of medical services, or 'medical consumption', has been the main subject of investigation for a number of national and international surveys (Lecomte, Mizrahi and Mizrahi 1974; Feather 1972) and a very long questionnaire could be formulated on this subject alone. Data on the medical and hospital services are most often available from existing administrative data, and it is a question of the practical use of these from the statistical point of view. However, as mentioned earlier, data relating to medical services received are a means of referencing health problems and for this reason are additionally justified. Nevertheless, if the main concern is with the assessment of health problems and risk factors, information collected on the utilization of services can be reduced to a minimum so that the interview is not lengthened indefinitely, and to avoid amassing data which cannot possibly be analysed in a reasonable time.

There are very useful potential applications of analyses of survey data linked with existing administrative data in planning health services. Just as it is important to know the individual and social characteristics associated with risk factors, if an attempt is to be made to modify risk exposure, so it is also important to know people's *attitudes towards services* if these services are to be made more accessible and better use of them encouraged.

17.4. The Canadian national health survey and its aims

In line with *A new perspective on the health of Canadians* (Lalonde 1974), the Canada Health Survey will endeavour to collect data which contribute to a definition of the various priority preventive measures to be implemented, in relation to those factors associated with lifestyle or environment. These measures can take different forms (health education, health promotion, health marketing, or legislation) but these will not be discussed here. It follows that the emphasis will be placed on health problems and risk factors, while the survey will also try to measure the corresponding psychological and social aspects so that the exact measures can be defined which will contribute to improving the standard of health; that is to say, which will reduce the number or intensity of health problems. For example, poor physical condition is acknowledged as a risk factor such that one could try to determine, by means of certain questions and suitable tests, the physical capacity of Canadian.

17.5. A method of determining priorities and attributable risks

A method of determining priorities

One method to determine the priorities, relating to the broader aspects described in *A new perspective on the health of Canadians*, is at present being developed at the Department of National Health and Welfare (1975) and is the subject of discussions with various Canadian provinces. This method anticipates three initial stages which can be summarized as follows:

Stage 1: classification of health problems in order of importance. The criteria used to measure the relative importance of various types of health problems (mortality, morbidity, infirmities and handicaps) can be based on mortality, hospitalizations, visits to the doctor, days of disability, or the cost to society. However, if several criteria are used simultaneously, they will have to be brought together in order to obtain a common unit of measurement which will constitute a certain type of health index. In the text following, this common unit of measurement will simply be referred to as a *unit*. If one were to base this unit on mortality alone, a *unit* could be the potential years of life lost before age 70 (Walter 1975).

The total number of *units* for which the health problem j is responsible would be indicated by: M_j, where $j = 1,2, \ldots, J$. The quantity J represents the total number of health problems existing in the whole population. This stage therefore consists of using all the available statistics reflecting the seriousness of the various health problems and combining them in the best possible way.

Stage 2: identification and measurement of the relative contribution of various contributing factors. Some of the factors concerned here correspond to risk factors while others do not. It is proposed to consider all the contributing factors corresponding to each of the following four categories:

(i) lifestyle factors;
(ii) environmental factors;
(iii) deficiencies in health care organization;
(iv) deficiencies in our knowledge of human biology.

The fraction of the health problem j which can be considered as being due to factor i will be represented by r_{ij}, where $i = 1,2, \ldots, I$. This represents the percentage contribution of the factor i to the problem j. I denotes the total number of contributing factors. For a given illness j, only a small number of factors i will be involved, and r_{ij} will therefore be zero for all the other factors.

Stage 3: contributions made by various factors and ranking of factors. For each factor i, the number of *units* F_i by which all health problems could theoretically be reduced by influencing factor i is calculated by adding together the number of *units* by which each of the health problems concerned would be reduced:

$$F_i = \sum_{j=1}^{J} r_{ij} M_j.$$

Therefore, if factor 3 plays a part only in illnesses 2, 3 and 5, the formula will be:

$$F_3 = r_{32} M_2 + r_{33} M_3 + r_{35} M_5.$$

Finally the factors are ranked according to the values F_i.

Finding the values to be given to the numerous variables indicated is obviously a heavy task. It is possible, however, to estimate the values of the relative contributions r_{ij} using the concept of attributable risk applied to all epidemiological studies concerning principal illnesses and associated risk factors.

Attributable risk

The notion of attributable risk is a relatively old epidemiological concept. Various aspects of this concept have been studied recently by Walter (1975, p27) who has been very successful in shedding light on the practical interest in this concept:

> 'Measures of attributable risk should be useful in setting priorities of preventive medicine by the establishment of the relative importance of different risk factors'.
>
> 'The possibility of life-style intervention studies in chronic diseases and heart disease, for example, demands an assessment at least of their potential benefit, and attributable risk may be one way of achieving this'.

Let us quickly sum up the various measurements associated with the notion of risk factors (Rouquette and Schwartz 1970, p.29), in cases where two groups of subjects are used, one exposed and the other not exposed to a risk factor, and for each of which a certain proportion of subjects are suffering or not suffering from a specific illness.

If: M_0 is the proportion of ill subjects in the non-exposed group,
M_1 is the proportion of ill subjects in the exposed group,
X is the proportion of subjects exposed,

the ratio $t = \frac{M_1}{M_0}$ is the classic relative risk used in aetiological studies to determine whether or not the factor under consideration plays a significant role. The difference $(M_1 - M_0)$ is also used to designate the additional probability of illness in the event of exposure.

However, the concept which interests us here is the attributable risk:

$$r = \frac{X(t-1)}{X(t-1)+1} \qquad (1)$$

which denotes the *proportion of all cases of illness attributable to a given factor.* It will be noted when considering the formula *(1)* that the attributable risk is determined if the relative risk, on the one hand, and the frequency with which the general population is exposed to such a risk, on the other, are known. These two values can be estimated by retrospective or cross-sectional studies in which the group of subjects is representative of the general population. Often, in a prospective study the frequency of exposure is unknown and must therefore be estimated by other means.

17.6. Priority preventive measures: the contribution of a national survey

By referring to Figure 17.1 and to the method indicated in section 17.5, the three contributions which a survey will make to a definition of priority preventive measures can be identified.

The first contribution is to the measurement of health problems. In countries which do not have a national household health survey, the only available data on health problems affecting the general population are mortality figures on the one hand and hospital morbidity data, and possibily certain statistics on the reasons for medical consultation, on the other. This is the case in Canada (Romeder and McWhinnie 1974), and it would appear that the majority of other countries are no better off in this respect. A national health survey should enable us to add some important dimensions of health problems such as handicaps, infirmities, mental illness problems, psychological problems and the disability resulting from each of the possible health problems.

The second contribution concerns risk factors. A national health survey would enable the rate of exposure of the whole population to the most important risk factors to be measured. These exposure rates, in combination with known measurements of relative risk, will enable the attributable risk to be defined.

The third contribution of the survey in planning preventive measures, concerns the question of associated individual and social characteristics. These should enable us to define with the necessary precision the profile (in terms of individual and social characteristics, including in particular the psychological and economic aspects) of the groups exposed to high risk.

This covers briefly the value of the survey in complementing other information in the overall measurement of health problems. It is equally important to mention the complementary role of a national health survey in relation to other epidemiological surveys. Without going into detail on the different types of epidemiological surveys possible, the distinction between aetiological surveys and descriptive surveys must be emphasised. The first is an integral part of an investigation, or a medico-social programme, and seeks to shed light on the causal chain at the root of a specific health problem; the descriptive survey, on the other hand, has general aims and serves to place health or social activities as well as research within a broader and more comprehensive field of action (Rouquette and Schwartz 1970, p.12). Epidemiological surveys of an aetiological type enable previously unknown risk factors to be identified and relative risks to be measured, whereas a national health survey must restrict itself to those risk factors whose role has been proven by acknowledged aetiological surveys, and which occur sufficiently often to be measured with a minimum of precision.

Is this to say that nothing can be deduced from the data of a national health survey, regarding the causal relationships between the various risk factors and health problems to be measured? Certainly not, and it will be of particular importance to attempt to measure the relationships between a group of risk factors considered together and various measurements of health problems; in other words, to attempt certain multifactorial analyses which are often impossible to carry out using aetiological survey data concerned with the measurement of only one or two risk factors. However, this is a question of secondary analysis which will be carried out after the first tabulations and descriptive analyses of the survey data have been made. Some very interesting analyses of the relationship between a group of risk factors, for example, number of hours of sleep, regularity of meals, physical activity, alcoholism and tobacco intake, and physical health status or mortality, have been carried out on certain populations (Belloc and Breslow 1972; Belloc 1973).

17.7. Other possible uses in planning

No attempt is made to give here an exhaustive list of the various possible applications. The major applications of a national health survey within the framework of planning preventive measures were covered in the previous section. Five other examples are given here of possible applications of the survey, each one corresponding to important aspects in the field of health, as it appears in Canada at least.

Linkage of survey data with administrative data

The collection of data on the utilization of health services which are already available in the administrative data files should be avoided in a national health survey. However, certain data on services received must be collected in order to reference health problems in the best way possible. The possible application of analyses of linked data–survey data and medical care and hospital insurance records–in planning better use and distribution of health services (Mizrahi and Mizrahi 1975) appears extremely promising.

The linkage of these two types of data offers the opportunity of finding out the extent to which the medical services are used by the individual during a whole year instead of being restricted to the previous two weeks, which is usually the case in interview surveys as a result of the limits imposed by the memory of the individual. By analysing utilization data for the period of one year, the bias, because the survey is carried out during a particular timespan–be it winter when usage is increased from the higher incidence of respiratory diseases or summer when holidays tend to diminish usage–is eliminated, and the data are richer. Data thus linked permit the comparison and analysis of the profiles of those people who do, and of those who do not, utilize medical services. These profiles will be defined as much by the various economic, social and individual characteristics which are covered in the survey as through data on health problems (disability, handicaps, infirmities). The corresponding analyses should define certain obvious inadequacies in the health services. However, they should endeavour in particular to define the profile of those groups which use the medical services to an excessive extent in order to provide the planners with the information to enable them to check the constantly growing 'medicalization' of our society.

Planning services for the handicapped

The health care delivery system generally endeavours above all to cater for acute illness, neglecting the problem of prevention for those subjects exposed to high risks, and the handicapped. Data on all the handicapped people in a given country should result in a better definition of the needs of this section of the population both in terms of specific health services and in terms of economic and social services.

Regional planning versus national planning

The importance of this question depends of course on the political system in operation and therefore on the level at which decisions on the question of health are taken. The demand for detailed information corresponding to a province, then a region, then a sub-region is obviously infinite. A point is soon reached where it is no longer possible to give sufficiently precise figures (corresponding to probability estimates) for very small geographical regions. One method has been proposed and implemented for obtaining disability figures corresponding to the 51 states of the USA (National Center for Health Statistics 1968). It consists of obtaining estimates, based on the hypothesis that the variable in question is distributed in the same way in geographical areas having the same socio-demographic profile (this profile based on a number of variables well defined elsewhere). Under these conditions a 'synthetic estimate' based on the average of those geographical areas having the same socio-demographic characteristics is obtained for a certain region. Such 'synthetic estimates' should be useful to the health planner.

Additions of specific modules of questions to the core survey

Possibilities are offered by a continuous survey scheme whose questionnaire is sufficiently flexible to enable changes to be made or modules inserted on topics for which it is not judged necessary to collect data every year. Thus, it was recently proposed that the Canadian project should include a sub-questionnaire on the consumption of non-prescribed drugs and the motives for this (for which a pilot investigation has been carried out) in order to obtain the basis information necessary to improve legislation with regard to the unrestricted sale of certain drugs.

Defining priorities

The fifth example concerns the direction which research in the medico-social field should take in order to arrive at a definition of priorities. If a country wishes to take an active part and not a passive one in the orientation of applied health research, data from a national survey should prove immensely useful. If it was found that the loss of 1 000 years of health life could be attributed to risk factor *A* and the loss of 100 years of healthy life to risk factor *B*, it would be natural to put considerably more effort into researching possible programmes to combat risk factor *A*.

Evaluation

This paper has merely described those applications which relate to planning. It is obvious that aspects of evaluation often overlap with planning activities. Generally speaking, it should be emphasised that the type of national health survey described here is not intended to be used for evaluating a specific health programme. However, there is an aspect of historical evaluation which a continuous national health survey could provide vis-à-vis certain variables such as risk factors. The extent to which the population is exposed to these factors will be measured periodically. This aspect might represent the only method of evaluating health and social programmes for which no experimentation is possible.

17.8. Discussion and conclusion

This text has tended to emphasise the way in which a health survey should complement existing health information. The improvement of all health statistics goes doubtless hand-in-hand with the willingness to plan health activities to match a certain overall concept. Statistics in general, and more particularly national health surveys, need to be improved through rational data use, and planners and analysts in the field of health policy should play a leading part in achieving this objective.

One of the important functions of the Canada Health Survey is coordination—to ensure two-way communication with those who will use the data in the future. With this aim in mind, a continuous liaison group, consisting of one delegate from each of the ten provinces, has been set up. The first two or three meetings of the group have clarified certain specific data requirements in relation to the general aims of the survey. This liaison mechanism is important in Canada where the provinces themselves are responsible for a large part of the health programmes. Hopefully, a better knowledge and understanding of the data to be collected will ensure that they are used effectively and quickly as soon as they are available. The problem of suitable analysis, and communication of the information to the various levels which will be likely to use it is an important one. The fact that the Canadian project is a joint venture of the central statistics organization and the ministry responsible for health is an *a priori* advantage. Data from the survey should, for example, be used as soon as they are available in medical education (social medicine, preventive medicine, epidemiology) as well as in the information directed towards health professionals.

The decision to set up a national health survey in a certain country will obviously depend on the quality of all health statistics available in that country; whether it is deemed preferable to improve certain statistics or to collect new ones which are thought to be more important such as morbidity statistics based on physician visits (by means of a survey of doctors, for example). It may also be decided to carry out epidemiological surveys on a small scale in a specific field. However, if the aim is to obtain a measurement of the state of health of the whole population in order to implement programmes of preventive measures, a national household health survey constitutes an essential tool which cannot be replaced by any other means.

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Paper 18

Health indicators

Y. Nuyens

18.1. Summary

This paper discusses the concept and uses of indicators; and the various conceptualizations of health. It goes on to define what is meant by the term health indicator, and discusses in detail the different indicators of distinct aspects of health which should be developed. It concludes by describing a research project, currently in progress in Belgium, which has been designed to provide data from which such indicators can be constructed.

18.2. Indicators

Indicators should be viewed as measures providing data and information on some individual or social reality. It is self-evident that the choice of the indicator must be governed by the purposes to which it is to be put. Apart from scientific research functions, these purposes fall into two broad categories: first, indicators are useful in recording the state and progress of nations; and secondly, they are useful in formulating policy-objectives. Since the systems evolved to carry out policy-decisions will usually generate data to fulfil the recording function, it is convenient here to consider indicators in the context of requirements for national policy decisions.

Indicators in a large number of cases operate as power instruments for various groups, in as far as to measure is to indicate the direction which policy should take. This does not imply any falsification or manipulation of indicators; although this is the case in certain countries which, for political reasons, give low suicide figures and remarkably low mental morbidity rates. The political functions of indicators refer simply to the fact that the availability of indicators, as well as the kinds of indicators that are developed, result from political options, consciously or unconsciously imposed by various groups. For example, in Belgium, a Commission for Information Processing was established in 1974 based on proposals from the Ministry of Social Security. Its aim was to collect data, through a computer programme, on medical performance analysed by the insurance code number of the medical treatment carried out; by physician(s) involved in the treatment; and by individual insured patients. These data would enable the authorities to gather useful information on the extent and the destination of expenditure on health care, on the distribution of different types of medical care, and the evolution of the usage of medical care. Through the interference of medical associations, this project was partially dropped. Only overall figures per groups of physicians and groups of insured persons were regarded as complying with the ethical code. In this way, a unique opportunity for the development of adequate indicators on expenditure and consumption was lost.

18.3. Health

It is important to give some attention to the notion of health, before dealing with health indicators. Indeed, the health indicators to be developed are highly pre-structured on the basis of the definition of health which is being used. The definition of health, however, is an extremely complex matter. Should it, for instance, cover:

- not being in a hospital;
- not being bed-ridden;
- being fit to work;
- or something even more complex such as general well-being?

Bearing in mind the well-known WHO definition, there are some comments which may be relevant. Health is not an absolute, but rather a relative notion. If it is agreed that health is more than the absence of infections or ailments, it should be concluded that every human being is partly ill, partly healthy; and absolute categorization as 'ill' or 'healthy' is not possible. Health is not a monolithic, but rather a multi-dimensional notion. In addition to the pure somatic well-being, there are also elements of mental and social well-being in question. Illness and health obtain their real shape from the interaction between these three aspects. Health is not a situation or status, but rather a process. On the one hand, what is considered ill or healthy is extremely dependent on time and culture (Illich 1975) and, on the other hand, health refers to a process of interaction between man and his environment, resulting in constantly changing forms of adaptation.

These remarks emphasize the need for a clear and operational definition of health in order to establish health indicators. Moreover, they also point out the limited relevance of traditional health indicators such as mortality and morbidity, of which more later.

18.4. Health indicators

Health indicators were usually defined as measures providing data and information on the basis of which the status or state of health of a given population can be evaluated. However, this approach is one-sided and incomplete. Borrowing the notions of input and output from systems analysis: data concerning the health status of a population pertain to the output dimension, whereas data concerning environmental factors (physical and socio-cultural) and health provisions fall in the input dimension. Hence, the indicators of the provision of health care do not provide any direct information on the health status of the population, although official documents, such as those of the WHO often suggest that they do. Input and output factors should in turn be distinguished from, and complemented by, indicators representing the state of health care, as well as measurements concerning effectiveness of the actions taken.

This shows that the term 'health indicators' covers a heterogeneous mixture of measures. It is essential to discriminate between different health indicators, because each of them has implications for a different aspect of health planning and health policy (Elinson 1973; Eylenbosch and Nuyens 1973).

Indicators of state of health

A preliminary remark which should be made here is that the significance and usefulness of biomedical indicators is decreasing, while that of sociomedical indicators is increasing. Nearly two decades ago, the WHO recommended that mortality data in various forms–life expectancy at birth, infant mortality rate, crude death rate, and proportionate mortality rate for ages fifty years and over–be used as indicators of the standard of living for international comparison.

Although mortality figures have undoubtedly been valuable parameters in the past, this is no longer true.

(i) They are negative because, by definition, they cover indexes not of health, but rather of poor health.
(ii) The relationship between mortality and morbidity is not always very clear, certainly not

when dealing with a predominantly chronic morbidity profile, and so they are inaccurate.

(iii) The mortality rate is incomplete in that it gives no indication of the duration of ill-health before each death.

The inadequacy of mortality rates as a measure of health status has led to growing dissatisfaction and demands for morbidity rates and other measures of social well-being. It is useful to distinguish between biomedical and sociomedical measures of morbidity. Biomedical indicators refer to morbidity figures revealing—on the basis of pathological analyses, physiological measurements or clinical diagnostic evaluations—the presence or absence of illness. They provide neither information on the extent and prognosis of the illness nor, which is even more important, on the impact of the illness on the individual concerned. Lying between the biomedical and sociomedical measures are the measures of functional physical capacity necessary to carry out what have been called 'activities of daily living': bathing, dressing, toileting, feeding, walking. Such measures, which can usefully be applied in evaluating the effectiveness of medical intervention in cases of disabling chronic disease, could also conceivably be used as health indicators for the general population.

Finally, under the influence of the 'social indicator movement', sociomedical health indicators were also developed. These imply an assessment of a valetudinarian individual's condition compared to the condition of others. Examples of this are:

(i) The Social Disability Scale, which examines the impact of illness on the performance of normal social roles—what is considered normal role performance is left to the judgement of the individual concerned.

(ii) The Sickness Impact Profile, developed mainly in the USA, which translates or transposes illness into a combination of behaviour variables such as social interactions, communication, work performance, mental activities, family relations, recreation, and mobility.

(iii) Jahoda's Indicators of Positive Mental Health, which develop a scale of mental health in terms such as attitudes towards oneself, self-realization, autonomy, empathy, resistance to stress, social maturity, and problem solving capacities.

A sociomedical health indicator should conform to two criteria: it should indicate both the actual functional level, and the way in which it is evaluated by the individual concerned; also the probability of change in functional level should be incorporated. Hence, functional level and prognosis are two central components in the health index. If optimal functioning is defined as 'conformity to society's standards of physical and mental well-being, including the performance of activities usual for a person's age and social role', an index for distinguishing different functional levels can be found in a combination of the following scales:

(i) a social activity scale, characterizing and systematizing those activities which may be expected as a function of a person's age and social role;

(ii) a mobility scale, referring to the capacity and the freedom to move from one place to another;

(iii) a physical activity scale, systematizing standing, walking, bending, and other physical movements of the trunk and limbs.

As far as the prognosis, or the chance of transition from one functional level to another is concerned, this can be done through a follow-up examination or through expert evaluation.

Such a health indicator has recently been developed by Patrick, Bush, and Chen (1973). A summary of it can be found, by way of illustration, in section 18.6.

Indicators of health influencing conditions

As this is elaborately dealt with in Paper 17, a few restricted comments only are added here. Except for epidemiological research, these kinds of health indicators have so far been given little attention. This is unjust, for in a multi-causal illness profile the environmental factors, both natural and socio-cultural, are gaining in significance. In the development of these indicators, explicit priority should be given to the so-called risk factors, that is to the detection and definition of health impeding factors. However, the positive definition of these health influencing conditions may result in the dictatorial imposition of health behaviour; thus they could lead to constraint, totalitarianism and coercion as unintended side-effects.

Indicators of need and demand for health services

Against the background of the rapidly growing costs of health care, there is, at present, international interest in the reasons for the great increase in the use of medical services, that is, medical consumption, which has recently taken place. An excellent synthesistic survey of the impressive research literature in this field was produced recently by McKinlay (1972).

Most indicators of the demand for health services are limited to the official medical consumption: number of doctor's consultations, number and period of hospitalizations, number of technical performances, extent of pharmaceutic consumption, and so on. Moreover, especially in countries with health insurance systems, the indicators are restricted to medical consumption covered, and paid for, by insurance. In this way, much of the major health care consumption pattern is ignored, making the indicator of the demand for health services incomplete and inaccurate. The construction of such an indicator should take into account all forms of consumption behaviour, including non-repaid consumption, and non-legitimated consumption—auto-medication, para-normal medicine, and self-care. An indicator of the demand for health services should not be limited to a description of the extent and kind of medical consumption, but should also have an explanatory, and hence predictive aspect. In other words, there is a clear need for indicators explaining why medical consumption varies between population groups. Such indicators should be built up first for the consumers of health care: socio-demographic indexes (age, sex, social status, area of residence, education) are essential, as are data on psychological factors such as knowledge of, expectations of, experiences of, and valuation of health care. In addition, the availability of health care, and the systems by which services function should be considered.

Since the use of health services is related to the prevalence of illness, differences in utilization rates may simply reflect different levels of health, not variations in accessibility. In evaluating the impact of any programme intended to improve access to the health care system (Aday and Andersen 1974), it is important to consider the use of services relative to the need for care. A recent paper by Aday (1975) describes one such attempt. Starting from the observation that among all the measures of need the number of days of disability is probably the most directly related to use of services, an index of access to health services based on a use-disability-ratio was developed. This indicator was subsequently used by the American Agency of Health Services Research in a nationwide survey of health service utilization and expenditure on health care. Although there are problems, it is clear that, basically, health survey systems do qualify as data sources for the construction of such a health indicator.

Indicators of health services

In the discussion of indicators of need or demand for health services the importance of the delivery system itself has already been pointed out. Indeed, the system will have a significant effect on the use of medical services: so that it is also essential for policy-makers to study the delivery system indicators. These pertain primarily to all the measures of the volume and distribution of resources, which might be derived from analysis of data on, for instance, the number of physicians and hospital beds, per unit of population and per unit of geographical area. Data on type of practice (solo, partnership, group); type of medical personnel (general practitioner, specialist, ancillary personnel); method of dealing with patients (number and kinds of consultations or admissions, type of medical personnel seen first); and the hours during which practitioner or facility is available would afford measures of the variables of organizational structure.

Finally, it should be pointed out that health services do not exist as objective, value-free realities, but are continually subjected to subjective evaluations by the (potential) consumers. There is a dialectic interaction between the structural moment (the existence of health services) and the cultural moment (evaluation by the client), lending form and content to the social fact 'health service'. It is, therefore, essential for policy making that indicators expressing expectations, experiences, satisfactions, dissatisfactions and preferences of patients are constructed for the various kinds of health services. In contrast with the other health indicators, little systematic attention has been paid so far to this aspect, which is a remarkable fact in itself, reflecting a certain form of policy making.

Indicators of the effectiveness of health services

According to Shonfield and Shaw (1972), effectiveness indicators measure the increase in the state of health to be expected from changes in health-affecting inputs such as housing, nutrition, medical services, sanitation and information services . The object of such indicators would be, for instance, to demonstrate how by varying one such input the state of health would respond during various time periods, or to show how different inputs may substitute for one another in promoting a given state of health or change of the state of health. Essentially, effectiveness indicators provide measures of the technical relationships between inputs and output. If 'health services' is taken to cover such a wide range of topics as listed previously, then these indicators theoretically fall in the category of the indicators of health influencing conditions. However, since it is probably easier to manipulate these technical relationships in health services (in the more conventional meaning of the term), it is justifiable to develop separate indicators of the effectiveness of health services.

Mechanic (1975) has published the results of research into the *Organization of medical practice orientations among physicians in prepaid and non-prepaid primary care settings.* Fee-for-service physicians spend more time in direct patient care activities than those in prepaid practice, and devote more time to each patient. The data suggest that prepayment systems encourage an 'assembly-line' type of practice which is less responsive to patients than the pattern characteristic of fee-for-service. Prepaid physicians work during scheduled hours and may deal with any increased load by processing patients more rapidly. Fee-for-service physicians tend to respond to increased demand by working longer hours.

De Melker (1973) observed, in a practice-analysing investigation, that the number of hospitalized patients from his primary care practice was much lower, for all age groups, than would be expected from the clinical morbidity figures in the Netherlands (namely 281 hospitalized patients instead of an expected number of 511). The following factors were suggested to explain this observation:

(i) concentration of diagnostic procedures in his practice;
(ii) intensive use of laboratory and X-ray facilities in neighbouring hospitals;
(iii) a high level of detection of psycho-social problems;
(iv) collaboration in the framework of a 'home-team'.

If the admission rate, standardized for age and sex, of his practice were in force for the whole country instead of the actual rate, theoretically approximately 1 000 million guilders ($300 million) could be saved on hospital admissions.

Both these examples show how the effectiveness of health services can be tested and measured by various criteria: time, number, kind and costs of health-affecting activities; and satisfaction of providers and consumers with different health services. However, effectiveness of health services should first of all be measured in terms of impact of services on the state of the health of a population. That this is often overlooked is also shown by these two examples.

18.5. Health survey systems and health indicators: an application

In the previous sections, attention has primarily been given to the different kinds of health indicators, some conceptual and methodological problems accompanying them, and the functions of these indicators for both research and policy.

The question now to be asked is which of the currently available data are adequate for the construction of these indicators? Certain existing administrative data are certainly useful, but their relevance remains restricted because they are collected for other purposes, usually in a format unsuited to their use as indicators. Thus preference must be given to survey data; health survey systems are adequate, not to say vital, instruments for obtaining data on the basis of which the above-described indicators can be constructed.

By way of conclusion I should like to demonstrate this by an outline of a planned national health survey in Belgium, already referred to in Paper 4, in which I participated as scientific coordinator. This example is introduced here because the previous theoretical considerations on health indicators were inspired by research experience, albeit limited, gained with this project; it is of course intended only as an illustration.

Background information

On 1 March 1975 a research project on the utilization, structure and functioning of the primary care delivery system and of the factors determining its use officially started. This project is a part of a national research programme in the social sciences, financed by the Ministry of Science Policy. The research project is inter-university (universities of Antwerp, Ghent, and Leuven); interdisciplinary (five medical sociologists and three medical doctors); and supported by the Scientific Society of Flemish General Practitioners. The project will take a minimum of three years and has a budget of 25 million Belgian francs ($600 000). The full-time research staff of eight is complemented by 15 experts, who provide advice and guidance on a part-time and indirect basis. A permanent advisory committee has been set up between the research staff and the responsible authorities to monitor the project.

Objectives

First, the research project was planned to collect, correct, and complete data essential for a health care policy in general and health planning in particular. It intentionally focuses on primary care, because this sector, for various reasons, will increase in importance in the future. Secondly, the project is intended to further the development of a number of health indicators, providing the policy-makers with an adequate and permanent instrument to measure and control the future evolution of health care. Finally, it is intended to pave the way to evaluating the effect of input variables (health care facilities) on output variables (state of health), so as to indicate new policy priorities.

Structure

So far, four stages have been defined for the project which will be synthesised into a fifth stage.

Analysis of health services. A morphological analysis of the primary care delivery system is planned. However, in Belgium, direct access to all forms of medical care is possible, so that this involves data on all medical services and personnel, and also on psycho-social services, such as social services and marriage guidance agencies. Services will be analysed by municipality, so as to build up a 'municipal index of services'. This index will subsequently be used as a stratification variable for a sample of communities.

Analysis of health care. For the communities in this sample, a detailed analysis of health services will be undertaken, to draw-up profiles of their actual methods of functioning. A basis of around 20 items has been defined for this analysis, which relate to goals, task concepts, task performances, task evaluation, therapeutic behaviour, organizational structure, technical equipment, systems of payment, accessibility, and so on. Special attention will be paid to analysing the types of complaints, symptoms, or whatever, for which medical care is sought, since this morbidity constitutes the first parameter of the demand for health care. This profile analysis will allow the development of a more sensitively graded index of health services.

Health interview survey. A survey of state of health will be carried out primarily by means of interviews, on a sample population drawn from the sample of communities. A broad definition of health will be used and thus the survey will be subject-orientated rather than disease-orientated (see section 17.3). Data will also be collected on demographic, socio-economic and environmental factors—age, sex, social class, housing, mobility, employment—which influence health status.

The results from this stage should provide indicators of state of health, and health influencing conditions. Moreover, by relating morbidity rates from the survey to morbidity rates in the detailed analysis of health service usage, some measure of the effectiveness of health services can be found.

Patients' health perspective. The population sample will also be asked to undertake in-depth interviews to investigate their views of the value of health; their health knowledge, and concepts of ill-health; their willingness to act on suspicion of illness; and their attitudes to health care: special attention will be paid to their degree of satisfaction with different aspects of health services. From these results an indicator of subjective health perspective can be devised, which can be used as a complement and corrective for the other, more objective, indicators.

Use of medical services. By controlling for the provision of medical services (from the detailed analysis of health care), and the need for health services (from measures of morbidity obtained from the interview survey), the extent and nature of medical consumption cannot only be described, but also, it is hoped, explained. Bearing in mind strictures made earlier, medical consumption will cover all aspects of health care, including auto-medication, self-care, and so on. These measures will provide an indicator of access to health services.

Conclusion

This rough, and very generalized outline of the research project, probably raises more questions than it answers. When the project is completed, it should be possible to reverse this trend.

18.6. Appendix: a system for an indicator of state of health

TABLE 18.1. *Scales and definitions for the classification of function levels*

Scale	Step	Definition
		Social activity scale
A	*Performed major and other activities*	*Major* means specifically–play for below 6, school for 6-17, and work or maintain household for adults. *Other* means all activities not classified as major, such as athletics, clubs, shopping, church, hobbies, civic projects, or games as appropriate for age.
B	*Performed major activity but limited in other activities*	Played, went to school, worked, or kept house but limited in other activities as defined above.
C	*Performed major activity with limitations*	Limited in the amount or kind of major activity performed, for instance, needed special rest periods, special school, or special working aids.
D	*Did not perform major activity but performed self-care activities*	Did not play, go to school, work or keep house, but dressed, bathed, and fed self.
E	*Required assistance with self-care activities*	Required human help with one or more of the following–dressing, bathing, or eating–and did not perform major or other activities. For below-6 age group, means assistance not usually required for age.
		Mobility scale
A	*Travelled freely*	Used public transportation or drove alone. For below-6 age group, travelled as usual for age.
B	*Travelled with difficulty*	(a) Went outside alone, but had trouble getting around community freely, or (b) required assistance to use public transportation or automobile.
C	*In house*	(a) All day, because of illness or condition, or (b) needed human assistance to go outside.
D	*In hospital*	Not only general hospital, but also nursing home, extended care facility, sanitarium, or similar institution.
E	*In special unit*	For some part of the day in a restricted area of the hospital such as intensive care, operating room, recovery room, isolated ward, or similar unit.
		Physical activity scale
A	*Walked freely*	With no limitations of any kind.
B	*Walked with limitations*	(a) With cane, crutches, or mechanical aid, or (b) limited in lifting, stooping, or using stairs or inclines, or (c) limited in speed or distance by general physical condition.
C	*Moved independently in wheel-chair*	Propelled self alone in wheelchair.
D	*In bed or chair*	For most or all of the day.

TABLE 18.2. *Classification of 29 function levels*

Level Number	Social Activity	Mobility	Physical Activity
L 30	Optimum Function (No Sympton/Problem Complex)		
L 29	Performed major and other activities	Travelled freely	Walked freely
L 28	Performed major but limited in other activities	Travelled freely	Walked freely
L 27	Performed major activity with limitations	Travelled freely	Walked freely
L 26	Did not perform major but performed self-care activities	Travelled freely	Walked freely
L 25	Performed major but limited in other activities	Travelled with difficulty	Walked freely
L 24	Performed major activity with limitations	Travelled with difficulty	Walked freely
L 23	Did not perform major but performed self-care activities	Travelled with difficulty	Walked freely
L 22	Performed major but limited in other activities	Travelled with difficulty	Walked with limitations
L 21	Performed major activity with limitations	Travelled with difficulty	Walked with limitations
L 20	Did not perform major but performed self-care activities	Travelled with difficulty	Walked with limitations
L 19	Performed major activity with limitations	Travelled with difficulty	Moved independently in wheelchair
L 18	Did not perform major but performed self-care activities	Travelled with difficulty	Moved independently in wheelchair
L 17	Did not perform major but performed self-care activities	In house	Walked freely
L 16	Required assistance with self-care activities	In house	Walked freely
L 15	Did not perform major but performed self-care activities	In house	Walked with limitations
L 14	Required assistance with self-care activities	In house	Walked with limitations
L 13	Did not perform major but performed self-care activities	In house	Moved independently in wheelchair
L 12	Required assistance with self-care activities	In house	Moved independently in wheelchair
L 11	Did not perform major but performed self-care activities	In house	In bed or chair
L 10	Required assistance with self-care activities	In house	In bed or chair
L 9	Did not perform major but performed self-care activities	In hospital	Walked freely
L 8	Required assistance with self-care activities	In hospital	Walked freely
L 7	Did not perform major but performed self-care activities	In hospital	Walked with limitations
L 6	Required assistance with self-care activities	In hospital	Walked with limitations
L 5	Did not perform major but performed self-care activities	In hospital	Moved independently in wheelchair
L 4	Required assistance with self-care activities	In hospital	Moved independently in wheelchair
L 3	Did not perform major but performed self-care activities	In hospital	In bed or chair
L 2	Required assistance with self-care activities	In hospital	In bed or chair
L 1	Required assistance with self-care activities	In special unit	In bed or chair
L 0	Death		

(Source: Patrick, Bush, and Chen 1975, References to sources of scale items available from the authors).

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Paper 19

National health survey systems in epidemiological research

U. Keil

19.1. Summary

This paper describes the three types of epidemiological study—descriptive, analytical, and experimental. It then discusses in detail the possible uses of, and limitations of, data from health interview surveys, health examination surveys, and studies of medical, administrative and insurance records in epidemiological research, with reference to the situation in the Federal Republic of Germany.

19.2. Introduction

The International Epidemiological Association has defined the main aims of epidemiology as:

> 'To describe the distribution and size of disease problems in human populations and to identify aetiological factors in the pathogenesis of disease. To provide the data essential to the planning, implementation and evaluation of services for the prevention, control and treatment of disease and to the setting up of priorities among those services.'

To fulfil these objectives of epidemiological research three types of studies can be used.

(i) Descriptive studies, concerned with observing the distribution and progression of diseases in populations.

(ii) Analytical studies, concerned with investigating by means of case-control (retrospective) and follow-up (prospective) methods hypotheses suggested by descriptive studies.

(iii) Experimental or intervention studies, concerned with measuring the effects on a population of manipulating environmental influences thought to be harmful and of introducing, in a controlled way, preventive or curative services.

The theme of this paper is the possibility of using data from national health surveys for the different kinds of epidemiological studies, but it should be borne in mind that there are at least three different methods of collecting data within national health survey systems.

(i) Health interview surveys (in the Federal Republic of Germany (FDR) Microcensus);

(ii) Health examination surveys in which measures of anthropometric factors like weight and height are made, and tests are undertaken for many other factors, such as blood pressure, blood chemistry analysis, dental state, and visual and audio acuity.

(iii) Investigations of records from medical institutions such as hospitals, health offices, general practices, sick funds, schools, army and social security.

How can the data from these different sources be used for epidemiological research and what contribution is to be expected?

19.3. Health interview data

These are data collected by interviewers from representative samples of defined populations. They cover the more prevalent diseases and injuries, and the social implications of such conditions; health and sickness behaviour; and patterns of medical care utilization for different aspects of health services (Lowe and Kostrzewski 1973). Since interview surveys also collect data on geographic location, age, sex, marital status, family size, income, occupation, education and so on, many interesting relationships between certain diseases and such variables may be discovered. Also different patterns of health behaviour, demand for medical care, and utilization of health services may be seen in the different social classes. The satisfaction of patients with the health care system can be assessed and information on the perceived need for medical care will be gained.

An assessment of 'need' for medical care by interview alone is possible for some conditions: for many somatic conditions, however, 'need' can only be assessed objectively by a medical examination. For example, the need for dental care can only be determined by a dental examination, whereas the perceived need, demand and utilization can be assessed by interview. Obviously the facts of the circumstances of illness or injury and the actions taken by the person, including the important topic of self-medication, can be obtained by household interview quite well, but for research projects in the field of descriptive epidemiology where it is important to obtain precise incidence or prevalence rates of certain somatic diseases these data have limitations. Although levels of some chronic conditions like bronchitis or rheumatoid arthritis can be determined quite accurately by interview, for many conditions there is a lack of completeness and diagnostic accuracy. There is also under-reporting of chronic diseases like cancer, mental illness, alcoholism, hypertension and an over-reporting of diseases like rheumatism. Very often the diagnosis may not be more than a description of symptoms and for symptomless diseases, like hypertension, the household interview will report no condition. The use of such data for epidemiological research into the aetiological of diseases is therefore restricted.

As has been mentioned, however, data from health interview surveys are useful for research into medical care utilization, health and sickness behaviour, and the social and economic implications of certain conditions. They can also provide an overall picture of health in a country and are useful for certain aspects of health planning. Obviously it is important for a health planner to know something about the perceived need, demand, and utilization for medical services in a population.

19.4. Health examination surveys

Health examination surveys are more useful for epidemiological research into the aetiology of diseases because they provide precise prevalence data which can be used for descriptive epidemiology and may help to generate hypotheses about aetiological factors of certain diseases.

Another contribution of health examination surveys is the production of 'normal values' of many anthropometric and physiological variables such as weight, height, blood pressure, blood cholesterol levels, blood sugar, uric acid and others like hearing and visual acuity. If health examination surveys are repeated regularly, time trends can also be assessed. The so-called 'normal values' of many physiological variables have been of interest to epidemiologists and clinicians alike, although today epidemiologists have abandoned this concept and are trying to find that point on the distribution curve where 'therapy does more good than harm' (Cochrane 1972).

Cross-tabulations of the more prevalent diseases with variables like age, sex, demographic area, socio-economic status, or household size can produce much interesting information: it is even possible that high-risk groups for certain conditions may be detected. If an examination survey reveals, for example, that people with hypertension are found more frequently in the lower economic groups of a population, it is the epidemiologists' responsibility to design studies to ascertain the reasons for such a distribution, and to give the health planner the data necessary to plan health services adequate to meet these needs. In the case of hypertension, for example, accurate prevalence data from national examination surveys have already made a valuable contribution to epidemiology and health care planning. Hypertension is one of the few 'high prevalence' diseases for which preventive measures can forestall complications on a community or even nationwide level. Nationwide control of hypertension cannot be planned and carried out without baseline data from examination surveys.

Health examination surveys do, however, have limitations which should not be overlooked.

(i) Because of the high costs of the examinations, the samples are relatively small and the volume of material on demographic, social and economic aspects of health does not compare with that from interview surveys.

(ii) Because of the small sample size, it is difficult to analyse data by small geographic areas or for small, high-risk occupational groups (MacMahon 1970).

(iii) Similarly, diseases of low incidence will not show up in the sample.

(iv) The non-response rate is relatively high.

(v) Because the health examinations are carried out only once a year, (if they are repeated on the same sample at all), it is difficult or practically impossible to diagnose diseases, such as multiple sclerosis, which require repeated and/or continuous observation and tests before they can be identified.

(vi) The data produced by national examination surveys are prevalence data and reveal a picture of the health or diseases status of a population only at one point in time.

Health examination surveys cannot substitute well-designed prospective epidemiological studies into disease aetiology in providing data for studies about the importance of certain risk factors for certain diseases. Neither can they provide the means for critical tests of epidemiological hypotheses. For instance, it cannot be tested by such data that a special vaccine prevents a certain disease; that clofibrate eliminates the risk factor hypercholesterolaemia; or that a screening programme for cancer of the cervix uteri lowers the incidence of this disease in the community. For the testing of such hypothesis experimental designs with control groups, or even randomized trials are necessary.

Prospective epidemiological studies in well defined populations have been performed to measure the long term trends of health and disease in a population and to identify risk factors, or even aetiological factors for certain diseases. The accuracy and detail of information needed in such prospective studies can never be obtained by national or regional health surveys or within any national health information system. National examination surveys serve however the purpose of providing the health planner and epidemiologist with crude descriptions of the most prevalent somatic diseases in a country or certain geographic area.

19.5. Surveys based on medical records

Investigations of population samples naturally reveal a picture of ill-health of the population biased to the 'healthy' side because hospitalized or institutionalized people are usually excluded. It is therefore necessary to obtain complementary data on the situation in general and psychiatric hospitals and other institutions.

Data from hospitals

Data from hospital patients can be valuable to epidemiology, apart from their possible use for case-control studies, if the hospital has a well defined catchment area so that the patient data can be related to the correct denominator for the calculation of rates. In the FDR, however, hospital data are frequently counted by cases and not by persons. Individual identifying numbers, which are common in Scandinavian countries, do not yet exist. This means that persons who are, for example, admitted three times in one year to the same hospital are counted three times, that means as three different patients. Such data give the health planner some estimate of the demand for, and utilization of, hospital care in a community but the data are less valuable in answering questions on changes in incidence rates of specific diseases over time.

Data from sickness funds

As about 92 per cent of the population of the FDR is covered by a social security insurance system, in which health insurance is included, one might expect that the data collected by the Krankenkassen (sickness funds) would be of great value to epidemiology. Unfortunately, the criteria to establish a diagnosis are unstandardized. Furthermore number and age structure of dependents of heads of household are often not known to the Krankenkassen. Thus the sickness funds' statistics can reveal only a picture of the utilization of medical services in the country: for aetiological studies their diagnostic validity is insufficient. These drawbacks of inaccurate diagnosis applies equally to the data from 'Rentenversicherung', general practices and health offices.

Data from disability insurance schemes

The Rentenversicherung (Disability Insurance Scheme) statistics provide data on the factors associated with disability. Special epidemiological studies are necessary to analyse the aetiological factors of the early stages of disability.

Data from health offices

The data collected at Health Offices reveal a picture of the importance of certain infectious diseases and other conditions or disabilities which have to be reported by the physicians of a community, and they have been used in some excellent studies on the epidemiology of tuberculosis by epidemiologists of health offices, (Pflanz 1973). However, the inaccuracy of notifiable disease statistics, due to under-reporting, is well-known and this naturally distorts the picture.

Data from general practice

Statistics from general practices have the same pros and cons as those mentioned with the sick funds statistics. They can, however, be utilized for the assessment of utilization of medical services at the ambulatory care level.

19.6. Other sources of data

Screening programmes

It should not be forgotten that the documented data from screening programmes for the early detection of diseases (Vorsorge und Krankheitsfrüherkennungsuntersuchungen) provide a huge amount of material which has not yet been evaluated by epidemiologists. The evaluation of the effectiveness of such screening procedures is of paramount importance.

Mortality data

Mortality statistics are available in the FDR and are used by the few epidemiologists. The analyses of mortality data for smaller geographical entities like census tracts is however uncommon. There are still legal difficulties in researchers obtaining death certificates to perform analyses of mortality data on the census tract level. It must also be mentioned that there are several States (Länder) where death certificates are destroyed after five years. Relationships between certain causes of death and socio-economic factors can only be assessed on an ecological basis, unlike the situation in the UK where it is possible to derive direct associations between social status and cause of death, because social data are available on each death certificate.

19.7. Discussion

A health interview survey in the sense of the US Health Interview Survey does not exist in the FDR: the 'Microcensus health survey' is a very small undertaking which cannot make an important contribution to epidemiology in Germany. A national health examination survey does not exist at all in the FDR.

The statistics from hospitals, sickness funds, general practices, and so on, described above, all have limitations for epidemiological research but can and should be used for certain tasks. It must be stressed that all efforts must be made to improve health statistics, and their dissemination, in the FDR. Death certificates should be accessible to epidemiologists, and researchers should be encouraged to analyse them also by smaller geographic areas such as census tracts.

The implementation of a well designed national health survey in the FDR would not only provide valuable information to Public Health Authorities but would also stimulate the still 'underdeveloped' fields of epidemiology, social medicine, and medical sociology. The establishment and implementation of a national examination survey is not realistic at the present time. While survey data are lacking and routine statistics show grave deficiencies, epidemiological register studies can produce meaningful data on important and frequent diseases like myocardial infarction, stroke, and certain cancers. If various register studies are combined in certain geographic areas, the chance arises to obtain a more general picture of the health situation in such an area. Register studies of this kind are therefore important tools in epidemiological research and community medicine.

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Paper 20

Economic aspects of health services and health information

E. Levy

20.1. Summary

This paper considers the problems involved in justifying health, and specifically health information, programmes in economic terms by means of RCB studies, in particular cost-benefit and cost-effectiveness analyses. It describes the value of RCB studies both as educational catalysts and in their more direct effects; discusses in detail the considerable problems in quantifying costs, effectiveness, and benefits in the health field; and also questions the whole concept of using these techniques in the health field. It then turns to the problems specific to health information, and concludes by suggesting alternative strategies for justifying the development of health information systems, pending the further refinement of economic techniques.

20.2. Introduction

One problem which faces this Workshop Conference is knowing whether, through cost-benefit and cost-effectiveness studies, or other economic techniques, a method of reasoning and assessment can be developed by which (i) the justification, particularly to public authorities, for the setting-up of certain surveys or information systems, and (ii) the choice between several information systems, or elements of information systems, can be attempted.

Indications will be given of just how complex this is: but it should be noted that the complexity is largely due to the fact that the information systems in question deal with aspects of health and health care. The estimation of costs, benefits, and effectiveness of health programmes is itself fraught with difficulties and some consideration of these is necessary before we move on to health information.

The considerations discussed here are based on the experiences of a system for the rationalization of budgetary choices (RCB) in the field of health in France. The French RCB was largely inspired by the American Programming, Planning, Budgeting System (PPBS), but it retains only one stage in this system, that constituted by cost-effectiveness and cost-benefit. However, this basis is broadened because the RCB method goes beyond the study stage to encompass the decision itself, its implementation and control, using information to modify or readjust certain factors taken into account in the initial stages.

It is now seven years since the French began to gain experience with this method and this period has provided the necessary perspective and an adequate amount of work to enable us to assess it. This work covers a wide range of subjects; the treatment of fractures using two types of hospital service; BCG vaccination; the systematic detection of cervical cancer; protection during the perinatal period; the prevention of suicide; the detection of handicaps in early childhood; health supervision in education; and so on. Recently the Ministry of Health has studied vaccination against influenza and the problem of hospital staff shortages using the RCB method. In the universities, a number of theses and dissertations have also consisted of studies of health problems from the same point of view of costs and results. However, the methodology used varies from one study to another, depending on whether they involve a comparison of health programme costs and benefits, or of costs and effectiveness. In the first case, the results of the measures envisaged are subjected to financial assessment and some formidable problems are encountered, such as estimating the price of a human life. However, the second method, which consists of measuring these results by means of one or several physical indicators (number of lives saved, deaths avoided, ...) is not always possible and is no less fraught with difficulties.

This paper will develop briefly four aspects:

(i) the nature of the contribution represented by such studies in the field of health;
(ii) the limitations of the techniques;
(iii) the questionable aspects which emerge from a more radical examination of the vision on which this technique is based;
(iv) the specific problems in applying these methods to health information.

20.3. Contributions of RCB in the field of health

There is a tendency to present the situation which existed before the development of methods such as PPBS and RCB in a slightly misleading way—as a phase of irrationality with regard to decisions on health matters. Thus the common sense and wisdom of erstwhile decision-makers is devalued; and rationality in health matters reduced solely to the methodology of the economist. It is no less true, however, that the planning and policy which have to be applied in the extremely complex field of health, are hampered by difficulties which cannot be tackled without a measure of stringent control and coherence in the approach and methods of reasoning used. To what extent, therefore, do the RCB approach and cost-effectiveness or cost-benefit techniques constitute progress?

Educational value

These steps forward in ideas have had first of all an indisputable educational effect. Never have so many studies been produced in the field of health in such a short period of time, and they have had some exceptional qualities.

They are multi-disciplinary studies which have led, because of the very nature of the problems encountered, to the cooperation of doctors, administrators, economists, and sociologists. Thus they have proved of mutual educational benefit. For doctors in particular, the general problems encountered in this work served to emphasize the need for a systematic gathering of data to enable the results of their actions to be assessed.

These studies have also had the virtue of effecting some decompartmentalization, since it has proved necessary to accept that representatives of several ministries or bodies (the Ministries of Finance, Health, and Education; INSERM; and the Sickness Benefits Authority, among others) should work together.

The RCB method has also presented the opportunity to broaden the horizon of prospective studies, to question, sometimes radically, traditional solutions, and to apply more stringent criteria for research into new solutions to health problems, because it requires:

(i) thorough consideration of objectives, explicit or implicit, for all health measures;
(ii) an exhaustive investigation of all possible means which might be used to attain these objectives;
(iii) systematic attempts, within the programme-objective structure, to match the objective with the means.

The difficulties encountered in the early studies enabled the inadequacy of the information system to be assessed and a number of justifiable improvements to be proposed. Thus, those epidemiological studies which are so necessary to measure the costs and results of health measures should logically develop more quickly. Similarly, local and national accounts analysis techniques are improved in so far as it is necessary to calculate more accurately the cost per type of illness, which is often impossible under the present circumstances.

Value in practical action

With regard to action, the effectiveness of cost-results studies has been more limited, but not negligible.

By using a language understood by the Ministère de l'Economie et des Finances (one might even say an actual code is imposed by this Ministry), these studies have resulted in the allocation of funds to finance a certain number of health measures and to develop the framework of study and research in this field.

Within the context of the preparation of the VIth French Plan, they have given rise to a new idea in health planning in terms of objectives and means, choices and priorities, embodied in the finalized programmes (for perinatal protection, or for home care for the aged, for instance). Above all, they have often given a degree of weight and credibility to the intuitive choices of the decision-makers and professionals in the field of health.

20.4. Difficulties and limitations of RCB studies of health

The difficulties and limitations encountered by specialists carrying out RCB studies in the field of health make it possible to develop a criticism of the method from 'within' the health system. This section discusses its possible applications, not its validity. Three types of problems will be considered in turn, according to how they relate to the assessment of costs, effectiveness, or the evaluation of benefits resulting from health measures.

Problems relating to costs

Firstly, one point should be emphasized—the costs referred to are not those of illness, but of the envisaged programmes of action to combat illness. In principle, this should be the easiest and least questionable of the cost-results studies. In point of fact, even here there are two major problems.

The difficulty of identifying or individualizing costs. This difficulty appears most particularly in studies of certain areas, such as:

(i) general hospitals, which do not take the sick person and his illness as a unit of cost in accounting—even in analysis—but rather the day, the medical discipline, or technical activities.

(ii) private organizations, the costs of which are not accurately known in the national accounts and statistics information system (industrial medicine within organizations, or the real cost of treatment in private clinics, for example).

(iii) *a fortiori,* non-economic costs of medical action are very difficult to expose: for instance, the psychological 'cost' of giving up tobacco to smokers.

The difficulty of predicting the pattern of costs. There is every reason to suspect that the cost of a health programme will not increase linearly as the programme expands, depending, for example, on whether it affects the whole population or a sub-group, or whether it expands over a shorter or longer timespan. The economist would like to be able to distinguish fixed and variable costs and would like to dissociate the average cost and the marginal cost to determine the point at which the marginal effectiveness of the programme, ceasing to be greater than its marginal cost, economically justifies its termination. However, in the majority of cases, the experimental data showing the laws governing the development of costs are not available (no more than are those relating to effectiveness). Therefore, the solution adopted, which consists of using the average cost, is no more than a broad approximation in working out the economic calculation.

Problems relating to effectiveness

In cost-effectiveness studies for health programmes, reference to one or several physical indicators avoids those obstacles or reservations which result from the need for an absolute financial indicator of the results of the measures envisaged: for example, by comparing the various means of forestalling accidents at birth, ratios of the cost of the child saved without *sequelae* by the various methods can be used, thus eliminating the problem of valuing the life of the child. There are still numerous difficulties.

Estimating the real effectiveness of health activities. Most typically, this involves programmes which act in a supporting role to others, in other words, which are indirectly effective through the implementation of other programmes. This is the case with training programmes (for certain types of specialists in the medical service) or research and study programmes. However, even for certain measures which are considered independent (increase in the number of antenatal visits, or development of the resuscitation of the new-born in maternity hospitals), the necessary experimental data may be lacking to measure correctly their effectiveness. Thus, studies have to be based on expert judgements, which rest on *a priori* estimations or very limited experience.

Problems associated with the development of synthesised indicators. Seldom do the health measures implemented have one sole objective. Thus, the measurement of effectiveness by means of one indicator is rarely practicable. In the case of measures directed towards improving perinatal mortality, one seeks both to save life (the indicator being the number of deaths avoided) and to avoid handicaps at birth. Different medical procedures can favour the first or second objective. How can these be compared? The solution which consists in retaining one single indicator which is of necessity synthesised (the number of lives saved without *sequelae*) has the disadvantage that it weights both aspects with the same significance. But how is it possible to weight accurately these two aspects which taken individually constitute a reduction of mortality on the one hand and morbidity on the other? More generally, how and on the basis of what criteria can the effectiveness of measures taken be weighted depending on whether they affect young people or old, active or inactive?

The difficulties which arise in discounting costs. The costs of proposed programmes will extend over a period of 10, 15 or more years, and it is logical to update the costs to their current values (in economists' jargon this is termed discounting). But it would be no less logical for the economist to discount the value of the results so that the lives saved well into the future are less valuable in current terms than those which could be hoped for in a short period of time. However, it can be seen that the writers of cost-effectiveness studies refuse to discount results, that is to consider 100 human lives saved without sequelae in 1982 to be equivalent to 50 identical units in 1975. Whatever the reasons, an asymmetrical factor is thus introduced into the processing of costs and of effectiveness which makes any comparison unsatisfactory.

Problems relating to benefits

The benefits selected for assessing the results of health programmes are none other than the costs avoided by these programmes. They are therefore simply the negative costs which are to be compared with the cost of implementing a programme.

Normally, but with variations according to the studies envisaged, three series of factors are selected to represent these benefits: in each of these catefories of benefits, and still more in all of them taken together, questions are posed which are a long way from being resolved.

The cost of medical treatment avoided. This is difficult to identify and to assess with accuracy.

as has been mentioned; but its significance is also questionable. Supposing that programmes were put into operation to avoid a specific aspect of morbidity; is it then certain that these programmes will result in a saving on present day treatment, and can any saving be considered as a resource which is released for use elsewhere? Is it not true that increased medicalization of society, and the dynamics of the health system itself result in the conservation of these resources and their use in offering more costly treatment to individuals suffering from these same illnesses? This question is linked with another question which has already been raised: what is the law governing the development of costs relative to the number of individuals affected (and also to the level of technical development, the state of the art, the aims, ...).

The extra productivity made possible by a reduction of morbidity and mortality. This second category of benefits has an even more dubious existence than that of avoided treatment, in so far as it consists of the supposed recovery of what is merely a series of gaps in society's production. This hypothesis can be opposed by arguing, first of all, that in countries with advanced development, there are numerous factors which make the machinery of production very flexible. Whether one uses an extension of working hours, the reserve pool of unemployed persons, the intensification of shifts, or any other means, it is doubtful whether the level of sickness absenteeism for any specific morbidity results in proportional losses in production. From the point of view of economic analysis this question returns to a basic debate which has not yet been settled: is the national level of production determined solely by the factor of supply, in which case the reduction of sickness should in fact increase it, or does it depend above all on the level of demand, in which case sick people are consumers; alternatively, is it a combination of these two forces and what laws govern their operation?

In any case, it seems wrong to consider the total amount of wages of individuals whose illness or death would be avoided as the value of the benefits obtained in terms of production: which is the normal indicator used. However, to select only a part of these wages is only possible and justifiable on the basis of observations made of the economic results of absenteeism on the macroeconomic level, observations which do not yet exist in any country. In addition, there exists a contradiction and a questionable value judgement with regard to medical products. Why should all production, other than medical products, be considered implicitly 'good' for society, its recovery being considered as a benefit, whereas the production in which doctors and paramedical staff are involved is considered negatively in terms of costs? There are also wages paid and revenues collected which go towards supplying the overall demand, indeed which further the economic growth of the whole, taking into account the actual dynamism of this field evidenced in the increased expenditure on health.

Finally, the assessment of benefits and production through the effective wages (or income) of the individuals preserved leads to consequences which are difficult to accept: biasing health measures in favour of the higher socio-economic status groups, or in favour of active persons and to the detriment of aged, inactive people.

Non-economic benefits. These include aspects such as the leisure and domestic activities made possible, suffering and emotional losses avoided, and the price of human life *per se.* Putting a value on these 'non-economic' benefits poses at least two major difficulties.

On the one hand, the objective bases for evaluating these factors are missing: what is the price of suffering, emotional 'losses' and so on? The conventional bases used are very debatable: for instance, the use of the minimum hourly wage to measure the value of one hour of leisure or domestic activity.

On the other hand, the list of these non-economic benefits is, it seems, endless, and excess enthusiasm, to justify health programmes, could lead to weighting of costs and benefits at will on one side or the other. One could even argue that by virtue of this immense reservoir of non-economic benefits, any health measures could be justified no matter how non-effective they might be on a technical level.

It is therefore questionable whether these extremely heterogeneous factors can all be added together. What would be the significance of an aggregate (the total benefit of a health programme) which results from the adding together of medical costs based on a certain reality and productivity (recovered) which is only theoretical; or from adding together economic benefits taken into account in the national economic figures and non-economic benefits which are not included in these figures under the present techniques of assessment? One could even say that this summation is nothing more than an inflated caricature of the communal aims of life: man (or woman) exists to work, do the housework, go to the cinema...

Optimum distribution of revenues

In the above discussions, there has been a progression from the difficulties involved in applying RCB in the health field, to a more theoretical consideration of the basis of the economic calculations in RCB. This leads on to the underlying theory of the optimum distribution of revenue. According to this, only those measures which improve the situation of certain individuals without any detrimental effect on that of others would constitute an increase in social welfare, unless there was some compensation between those who gained and those who lost. Thus, for a programme to combat tobacco consumption, justification from the point of view of social welfare implies that the community would be able to take from the totality of 'gains' resulting from these measures, something to compensate for the 'losses' suffered by the smokers in the sacrifice which they would have to make.

One can assume that this hypothesis is satisfactory if the measures taken are small in scale, that is, they are marginal alterations in the situations of people, or where effective measures are taken to compensate those who bear the loss. However, this is no longer the case with overall policies of considerable significance, and *a fortiori* with general health planning which implies fairly substantial structural alterations. Under these conditions, the economic calculation concerning the weighting of costs and effectiveness or benefits, losing an important factor in their theoretical justification, can no longer pose as a guideline towards the optimum.

20.5. Towards a reassessment of RCB in the field of health

Criticisms levelled at RCB studies in the field of health are increasingly moving beyond the consideration of particular aspects, and are tending to reject the whole underlying concept as an unacceptable caricature of the decision-making processes in the health sector. This wholesale rejection is based on two main arguments.

Multiplicity of objectives

This again draws into play the unquantifiable aspects of health care and has often been the subject of arguments from the Centre d'Etude et de Recherche sur le Bien-Etre. The concept distinguishes between the technical effects of health programmes and the non-technical, especially psychological, effects such as the response to calls for help, reassurance of patients, and so on.

The costs of certain measures can only be fully evaluated if one recognises all these effects. Non-technical effects, which are generally obscured by the dominant system of values are not taken into account in either cost-effectiveness calculations or even in the cost-benefits figures, so that these calculations are not complete and cannot constitute a correct method to aid decision-making.

The multiplicity of decision-makers

The concept here is that RCB studies are set up as though there is one decision-maker (perhaps a mythical 'State') who bases all decisions on a single rationale. In fact in any health system there are many decision-makers at various levels, the patient seeking health care, the doctor treating a case, or health planners, who all make their decisions from different motivations. In this situation even cost-benefit analyses which differentiate the type of agent are not suitable for such a multi-criteria choice situation.

20.6. The specific problems of health information

As far as the production of health information is concerned, there are two levels of problem to which economic techniques are applied.

(i) Is there justification for the initiation of a new survey or other health information system?

(ii) Given that information is to be collected on a specific topic, what is the best system to use?

It should be emphasized again that the comments in section 20.4 on the application of techniques in the health field generally, apply equally to health information, but there are specific problems in the information field and these require some elaboration.

Costs

There are three problems related to the costs of information. Firstly, one must identify the costs. When information is obtained from routine medical records, for example, the costs of collection are hidden in the administrative system. In considering health surveys, one can define at least two categories of cost:

(i) direct costs which include all salaries, data processing, equipment and all other accountable expenditure;

(ii) social costs which cover aspects such as the time of the sample participating in surveys, or the time spent persuading doctors of the usefulness of the results, and which cannot be assessed in financial terms.

Good cost-benefit or cost-effectiveness studies should certainly be able to identify all costs.

Secondly, there is the problem of apportioning the costs between the various stages of the information process–planning, data collection, processing, and utilization. It has been emphasized in previous papers that if resources, and hence overall costs, are not correctly distributed between these stages, the effectiveness of the information system is greatly decreased. But there are often problems in this distribution and the allocation of costs is by no means simple–especially when considering the utilization stage. It should also be mentioned that an inter-relationship between the level and the effectiveness of the expenditure–that is to say that there are situations where the value of the information produced by a system can be increased disproportionately by an increase in expenditure minor in relation to the total already spent.

The third problem is a very complex and more general one which arises in considering costs in any field, not just information. It concerns cost development. Usually, when the costs of producing a particular set of information are assessed, this is done for a specific case–for example, for a given range of detail in the data and sample size. There is a tendency to assume a linear relationship for costs, so that if the sample size is doubled the costs are doubled, but there is no reason for this assumption; the relative costs may increase or decrease. Here one must be absolutely strict from the economist's point of view, and measure not only unit costs–say the average cost of one household interview–but also the marginal cost of increasing the sample by a given number of households. Only when these marginal costs are known can the economic decisions on sample size, or whatever be put forward for consideration to be related to the statistical, epidemiological, and other decisions.

There are also great variations in costs between different information systems. Routine data extracted from administrative records will appear less costly than a new survey, because a larger proportion of the costs is likely to be hidden. This example is given to emphasize the limits which exist in defining costs and the danger of reaching conclusions without due consideration.

Results

This neutral term is used advisedly since benefit or effectiveness have very specific meanings in the economist's language; benefit is a monetary term and, in the context of information systems, monetary benefit is not applicable. The main problem is to identify the beneficial results of information, or more exactly, to express them as quantifiable indicators. Several reasons have been put forward in the previous papers to explain this problem. The first difficulty comes in attempting to identify all the users of information and in specifying their needs; and possibly there is a case for surveys to measure perceived need for information similar to those which measure perceived need for health care. However, a more serious problem is in ensuring that even when information is produced to meet a specific need, decisions are based on this information.

Lastly, and this is the major problem, in the jargon peculiar to cost-benefit analysis, information programmes, like research programmes, are only supporting programmes, that is to say programmes the effectiveness of which is indirect and can only be quantified after contingent action programmes have been undertaken. The great breadth of the problems involved in assessing the results of health information, means that the indicators chosen to express these results must be selected most carefully. One could derive an indicator based on the amount of information on health provided per person but there is little in this with which to evaluate the usefulness of the information. At the other extreme, one could attempt to relate the information to the improvement in health status of all or some of the people involved. But this again leads to the problems of assessing years of life saved, volume of production recovered, and so on, which were mentioned in relation to medical programmes. In this context the conclusion would undoubtedly be that *ad hoc* surveys are more effective than general surveys because they lead to the identification of a particular disease in a population and thus to medical intervention; again one can only point out the dangers of conclusions which are based on limited information!

20.7. Conclusion

The reasoning which insists on the justification of health programmes, and specifically health information systems, by weighing the cost and measuring the results seems totally inadequate. Possibly a better solution is to demonstrate by systems analysis, the impact which information has on all aspects of decision-taking in the health field—in clinical medicine, preventive medicine, medical research, and so on.(This has been discussed in detail in Papers 17 and 18.) Only on this very wide basis is it possible to justify the efforts that a community may be asked to make in the development of an information system. This situation is by no means unique; for instance, it is customary to accept that part of the national effort is dedicated to general research, without specific benefits being quantified.

These conclusions show pessimism as to the value of cost-benefit and cost-effectiveness studies in this field, and are critical rather than constructive. It is perhaps worth noting that the conclusions which are slowly being reached in France are in accord with the American point of view, which is much more cautious about using these methods in certain fields, including health, in spite of the enthusiasm shown in the first years of the PPBS. However, the development of a decision-making science in the field of health has hardly begun: the economist can contribute, but on condition that he acknowledges the limitations of his techniques and seeks to go beyond them in the allying of his viewpoint with those of the other health specialists.

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