

RECORD LINKAGE

SUGGESTIONS APPROVED BY THE SOCIETY FOR SOCIAL MEDICINE AT THE 1968 ANNUAL GENERAL MEETING

1. INTRODUCTION

1.1 For many years the records of patients admitted to hospital used to be filed separately in the hospital record department until eventually all the records of patients treated in one year by an individual physician or surgeon were bound together. Thirty years ago this system began to be replaced by the 'unit system' under which all the records at one hospital relating to one patient were brought under a single cover. This system proved to have so many advantages from the point of view of practical medicine and scientific advance that it has now become universal and no one who has used it would willingly revert to the old method.

1.2 Other medical records, however, are still kept separately. Each hospital has an independent system, and a patient's admissions and attendance at one are not related to those at another. Birth, marriage, and death certificates are filed separately without cross-indexing. No attempt is made to connect general practitioners' records with those collected by the local authorities, the hospitals, the Ministry of Social Security, or the Registrar General. And although the unit system has made so much difference to the value of hospital medical records, it is ignored for the purpose of hospital activity analysis, which is still concerned solely with events without reference to the individual to whom they occurred.

2. REASONS FOR PROPOSALS

2.1 The value of bringing together medical information about the individual was recognized by Farr more than 100 years ago and has been stressed repeatedly since. Recent changes in society, however, have sharply increased the need for record linkage and have made it much easier to bring about.

2.2 In particular:

(i) the central problems of medical care and medical research have shifted from acute conditions of brief duration, that occur soon after the events that caused them, to complex chronic conditions that may not appear for many years after their causes have disappeared;

(ii) familial and genetic factors have become of increasing importance in the development of

disease, and greater understanding of population genetics is needed for the development of informed policies for genetic counselling and population control;

(iii) the organization of medical services and the methods of prevention and therapy have become more complex and more dependent on accurate information about the needs of the population and the characteristics of the individual subject;

(iv) population movements have increased, repeat treatments have to be given in different places, and the follow-up of individuals for scientific purposes has become more difficult;

(v) with the introduction of the National Health Service, the great mass of separate health and sickness data has become the responsibility of the government; and

(vi) the development of the electronic computer has revolutionized the speed of searching for and sorting data and has reduced by many orders of magnitude the space required for their storage.

2.3 The introduction of a national system of linked records, based on the individual, is of great interest to all who are professionally concerned with epidemiological and genetic research and the organization and efficiency of the health services. A simple system limited to the files of existing vital certificates, the hospital in-patient enquiry and activity analysis, the mental health enquiry, and the regional cancer registers would be of great value now, and could be made more valuable in the future by the inclusion of other records as experience showed was both necessary and capable of being handled (for example, insurance records, general practitioners' and school medical records, and drug prescriptions).

2.4 The immediate value of the system would be to:

(i) facilitate the exchange of information necessary for the patient's treatment between medical centres;

(ii) identify groups of subjects at special risk and requiring surveillance;

(iii) permit the development of a proper

intelligence service within the National Health Service, so that the effect of its operations on the individual could be assessed;

(iv) create the opportunity for large-scale investigation of the inter-relationship between diseases;

(v) facilitate the study of the health experience of groups of individuals characterized by possession of specific genetic markers or exposure to specific agents; in particular, to allow the routine examination of possible harmful effects associated with new industrial processes and the recognition and measurement of the risks attendant on the use of new drugs; and

(vi) facilitate the study of demographic trends in relation to the genetic constitution of the population.

3. NECESSARY PRE-CONDITIONS

3.1 For records to be linked it is essential that each should contain sufficient identifying data to enable it to be assigned to the appropriate personal file. The use of a single identifying number on all health records, as is now the practice in Scandinavia, would greatly facilitate linkage but it is not necessary to wait for agreement on the use of a single number for N.H.S. and insurance purposes before the records that are medically most important can be brought together. This can be effected so long as the records contain all current names, maiden (birth) surname, date of birth, place of birth, sex, current address, and, whenever possible, the N.H.S. number.

3.2 All of this information is not now given on the records which it is proposed should be linked, but the great majority is and the rest could be added without great difficulty. In this respect it is a major advance that the Registrar General has, within the last year, proposed the inclusion of:

(a) mother's and father's place of birth in the child's birth entry;

(b) the date and place of birth of the deceased and the maiden name, when the deceased was a woman who had married, in the death entry; and

(c) the dates and places of birth of the bride and bridegroom in the marriage entry.

DIFFICULTIES

4.1 Objections to the scheme are based mainly on the grounds of cost and loss of confidentiality of medical information.

4.2 It is difficult to estimate what the cost would be. If the system had to be built up from the beginning it would certainly be enormous. All the records which it is proposed should be linked are, however, already collected and filed and many of

them are reported independently to central registers. It is not suggested that the linked record should utilize new material, but that it should be constructed out of records that are already collected and filed. By rationalizing the collection and distribution of records it would produce many savings, for example, the necessity for separate notification, recording, and follow-up of cancer patients (which alone must cost between £250,000 and £500,000 a year) and the need for an independent file of national health service patients maintained for the purpose of paying general practitioners.

4.3 The fear that the confidential nature of the medical record would be diminished is unfounded; in some respects the reverse would be true. In particular, it may be noted that:

(i) once the data have been coded and punched, they are less accessible than the plain language data currently stored in hospital records departments, regional cancer registries, etc.;

(ii) there is no difference in principle between a coder reading a record for the purpose of card punching and a clerk reading it for the purpose of hospital analysis;

(iii) most of the output would be in tabular form and unrelated to individuals;

(iv) patients' names associated with clinical information would be available only to bona fide research workers for approved purposes on the basis as at present, or to a patient's own doctor for direct benefit of the patient, as is now the case when a patient is transferred from one doctor (general practitioner or hospital) to another;

(v) malicious search of a magnetic tape or disc file would require a computer operation and be more difficult than a similar search in a conventional medical records department; and

(vi) the individual's record would be used only for health purposes and should be made unavailable for any other purposes (for example, tax identification) by law.

5. CONCLUSION

The practicability of large-scale record linkage using the type of identifying data that are available in Britain has been demonstrated by Newcombe in Canada and Acheson in Oxford. The desirability of introducing a national scheme for linking selected vital and medical records has been emphasized by the Medical Research Councils in England and Canada and steps have been taken to introduce such schemes in Scotland and Northern Ireland. The size of the population in England and Wales makes the introduction of a similar scheme in this country more difficult, but it also makes the value of the scheme much greater.