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HOSPITAL CLINICAL RECORDS

Symposium at the King's Fund Centre
Wednesday 8 May 1985
In collaboration with
The Wellcome Institute for the History of Medicine
Contemporary Medical Archives Centre

PROCEEDINGS

King's Fund Centre
126 Albert Street
London NW1 7NF

King Edward's Hospital Fund for London

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INTRODUCTION

WHY KEEP HOSPITAL CLINICAL RECORDS?

A leader published in the British Medical Journal on 26 January 1985, on the subject of hospital clinical records, mentioned that a meeting was to be held at the King's Fund Centre to discuss problems associated with these records. This took place on 8 May 1985 and was attended by historians, clinicians, epidemiologists, administrators, archivists, representatives of relevant organisations, and other people whose interest in the topic was well known. There was a good response and enquiries following the leader illustrated that interest in the subject is widespread. However, numbers at the meeting were limited to encourage discussion. A list of participants and a copy of the day's programme are included in these notes. Papers were distributed before the meeting and briefly introduced by their authors; these papers with a report of the introductions form the main part of this publication. Each paper was discussed during the morning, and the afternoon was devoted to wider discussion, using as a basis the fact sheet which appears at the end of this report. Proceedings were both stimulating and informative, comments were of a high standard, and there was a valuable interdisciplinary exchange of information.

Dr Stephen Lock, Editor of the British Medical Journal, chaired the symposium. In welcoming the participants, he reminded them of its purpose: to consider how to deal more effectively with the problem of the ever-increasing volume of hospital clinical records. He recalled that the subject had been addressed before. In fact, at an earlier symposium on the preservation of medical and public health records at the King's Fund Centre in 1977, the question of hospital clinical records (whilst not specifically addressed) had been noted. Since then the Wilson Committee's report on Modern Public Records(1) had been published in 1981, and the Government White Paper(2) in response to it in 1982. It was thought that the time was ripe for further discussion specifically on the problem of hospital clinical records. The White Paper had suggested that problems of volume and confidentiality, together with doubts as to their long term value, presented a strong case for the removal of clinical records from the requirements of the Public Records Act 1958. No action has been taken on this point, and these records remain public records.

Dr Lock pointed to two major defects in the present situation. On the one hand, clinical records are closed to researchers for 100 years; this may be a barrier to clinical as well as to other types of research. On

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(1) GREAT BRITAIN. PARLIAMENT. Modern public records: selection and access. Report of a committee appointed by the Lord Chancellor. (Chairman, Sir Duncan Wilson). London, H.M. Stationery Office, 1981. pp.xiii 256. Cmnd. 8204.

(2) GREAT BRITAIN. LORD CHANCELLOR'S DEPARTMENT. Modern public records. The Government response to the Report of the Wilson Committee. London, H.M. Stationery Office, 1982. pp.29. Cmnd. 8531.

the other hand, indiscriminate preservation of a huge accumulation of individual clinical records could prove, paradoxically, to be a block to the transmission of valuable information. He commented that, in view of the mass of records created, and the widespread reluctance to destroy any, careful selection seemed the only way to ensure that important material survives.

Problems caused by the enormous bulk of hospital case records were recognised by all, and discussion throughout the day concentrated on the question of what should be done with them. Various important themes arose in discussion and were seen as necessary background to the problem, of which anyone contemplating the main issues must be aware. Thus the legal position of the records, the difficulties caused by the 100 year rule, and the question of confidentiality were repeatedly raised, as it was recognised that any proposed solutions needed to be seen in context.

There was agreement by all participants that there is a significant difference between the older bound volumes and the modern case files which were introduced in the 1920s and 1930s. Whilst most users of the material in both forms might see them as continuous series or runs, differences in their content and physical make up were usually reflected in different methods of storage and in the attitudes of people responsible for them; thus alternative solutions for dealing with the records are needed. Of the older clinical records, some (sometimes only pre 1900) had found their way into local record offices, but very few record offices were prepared to take modern case files.

Various opinions were aired as to the appropriate places for storage and who should deal with the records. Should a medical records centre be established? Should regional health authorities appoint archivists? The Scottish example was cited here, but even there only a minority of the fifteen health boards employ archivists, and those only on an ad hoc basis. Moreovoer, such a solution had been rejected by the Government. Was the answer to microfilm? Many hospitals are now microfilming but there are two major difficulties: firstly, could retrospective microfilming be justified when it would involve vast expense? Secondly, even if kept in archival conditions, the lifespan of microfilm is uncertain. In fact, the conditions in which many hospitals keep microfilm are far from ideal, which certainly means that it will not last for ever. The answer seems to lie in some kind of sampling or selection. Various methods of doing this were raised, but there was time to do no more than touch upon one or two of them. It was suggested, for example, that selection might be by geographical area. Or there might be concentration on saving a wider field of health records, including general practitioners' records which at present are destroyed three years after the death of patients; this would demonstrate how the NHS had worked and, for example, what proportion of patients were referred to hospitals within a given area. It was also pointed out that the existence of indexes to the material was crucial and needed to be recognised when it came to decisions of selection or destruction.

It appears that use of these records is still fairly small, and it is not clear to what extent this reflects the comparatively recent dates of stored material, difficulties of access and the unawareness of its existence and value to social historians. Whilst the discussion did not present any new scheme for dealing with these records (and indeed it had not been anticipated that it would), it strengthened the resolve of participants that some improvements could be effected. It was generally agreed that

the present status quo, whereby the records survive by luck or at best through haphazard concern, is a highly unsatisfactory state. Any attempt to introduce at least a greater element of guidance could only be to the good.

In concluding the day's proceedings, Dr Lock said that he hoped that some definite proposals would emerge, and to this end he suggested the formation of a small working party which would look into the possibility of drawing up a scheme to submit to the Department of Health and Social Security. Improved liaison between hospital administrators and bodies such as the Department and the General Medical Council was vital, and their role was essential in assisting with issues such as the reduction of the 100 year closure period or clarification on the use of clinical records by bona fide scholars. In addition, the problem of the ever burgeoning body of files being created daily, and the possibilities of introducing and preserving summary sheets only, needed closer investigation so that future generations are not faced with the same problem of bulk. Finally, there was an immediate necessity for greater information about what existed at the moment, especially in hospitals; it was agreed that the Contemporary Medical Archives Centre and the Public Record Office would undertake a survey.

The symposium was hosted by the King's Fund Centre and organised by Mrs Alexandra Nicol and Miss Julia Sheppard. Dr Meryl Foster, of the Public Record Office, kindly took notes of the meeting, and the summaries that accompany the papers were written by her.

AN/JS/km
1 August 1985

King Edward's Hospital Fund for London

King's Fund Centre
126 Albert Street London NW1 7NF

HOSPITAL CLINICAL RECORDS
Symposium at the King's Fund Centre
Wednesday 8 May 1985

In collaboration with
The Wellcome Institute for the History of Medicine
Contemporary Medical Archives Centre

Chairman: Dr Stephen Lock
Editor, British Medical Journal

9.30 am	Registration and coffee
10.00	Introduction Why the material should be kept Chairman
10.30	The legal position Mr A P Andrews Head of Legal Services South East Thames Regional Health Authority
10.55	What statistical information is available? Dr Michael Alderson Office of Population Censuses and Surveys
11.15	Coffee
11.30	What records are kept now? The present scene Alexandra Nicol, Public Record Office Julia Sheppard, Wellcome Institute
11.50	Explanation of the problem Brenda Marshall (formerly of Addenbrooke's Hospital) Jonathan Pepler District Archivist, Tower Hamlets Health Authority
12.10 pm	Problems of confidentiality Dr Michael O'Donnell
12.30	Problems of bulk: how government departments cope Michael Roper, Public Record Office
1.00	Lunch
2.00	Discussion of identified options (see discussion paper H - fact sheet)
4.00	Tea, disperse

AN/JS/km
19 April 1985

HOSPITAL CLINICAL RECORDS
Symposium at the King's Fund Centre
Wednesday 8 May 1985

List of those who attended

*	Dr M R ALDERSON	Chief Statistician, Medical Statistics Branch, Office of Population Censuses and Surveys.
	Dr K M ALLSOPP	Under Secreatry, Medical Defence Union.
*	Mr A P ANDREWS	Head of Legal Services, South East Thames Regional Health Authority.
	Dr E R BECK	Consultant Physician, Whittington Hospital.
	Sir Christopher BOOTH	Director, Clinical Research Centre.
	Mr I BROWN	Head of Common Services (Records), Ministry of Defence.
	Dr W F BYNUM	Assistant Director (Research) and Head of Academic Unit Wellcome Institute for the History of Medicine.
	Mr A CAMERON	Head of Manuscripts Department, University of Nottingham.
	Mr T A COSGROVE	Administrator, The National Heart Hospital.
	Mrs B CRAIG	Archivist, Archives of Ontario, Canada.
	Sir Richard DOLL	Imperial Cancer Research Fund.
	Dr D DOW	Archivist, Greater Glasgow Health Board.
	Dr M FOSTER	Assistant Keeper, Public Record Office.
	Mr E J FREEMAN	Librarian and Deputy Director, Wellcome Institute for the History of Medicine.
	Dr H L FREEMAN	Senior Consultant Psychiatrist, Salford Health Authority.
	Ms L A HALL	Assistant Archivist, Contemporary Medical Archives Centre, Wellcome Institute for the History of Medicine.
	Mr D HAMILTON	Wellcome Unit for the History of Medicine, Oxford.
	Mr A HARRISON	Public Record Office of Northern Ireland.
	Dr M A HEASMAN	Director, Information Services Division, Common Services Agency for the Scottish Health Service.
	Mr J KEENE	Formerly Printing Service Manager (Reprographics), Public Record Office.
**	Dr S LOCK	Editor, British Medical Journal.
	Dr I LOUDON	Wellcome Unit for the History of Medicine, Oxford.
*	Miss W B MARSHALL	Formerly Patients Services/Planning Administrator, Addenbrooke's Hospital, Cambridge.

* Speaker

** Chairman

continued/...

	Mr K MORTON	Associate Director, King's Fund Centre.
	Mr J G MYSON	Regional Systems Development Officer, South East Thames Regional Health Authority. (Honorary Secretary, Association of Health Care Information and Medical Records Officers).
*	Mrs A NICOL	Liaison Officer, Public Record Office.
*	Dr M O'DONNELL	Author.
	Dr W L PARRY-JONES	Consultant Psychiatrist, Warneford Hospital, Oxford.
*	Mr J PEPLER	District Archivist, Tower Hamlets Health Authority.
	Dr J V PICKSTONE	Department of History of Science, University of Manchester Institute of Science and Technology.
	Dr G C RIVETT	Principal Medical Officer, Department of Health and Social Security.
*	Mr M ROPER	Records Administration Officer, Public Record Office.
*	Miss J G A SHEPPARD	Archivist, Contemporary Medical Archives Centre, Wellcome Institute for the History of Medicine.
	Mrs C SHORT	South Yorkshire County Record Office. (Honorary Secretary, Society of Archivists).
	Mr K J SMITH	Inspecting Officer DHSS, Public Record Office.
	Mr W R WINTERTON	Consultant Surgeon (Obstetrics and Gynaecology), Middlesex Hospital.

* Speaker

DISCUSSION PAPER A

The legal position

Mr A P Andrews
Head of Legal Services
South East Thames Regional Health Authority

HOSPITAL CLINICAL RECORDS

THE LEGAL POSITION

The starting point for any consideration of this topic must be to ask: "What is our purpose in maintaining records and keeping notes?" All too often we lose sight of the fact that they exist primarily to facilitate the care and treatment of the patient and their use in any other way, without appropriate consent, constitutes a breach of confidentiality. On the other hand there can be no question of a breach in cases where information is given to another person who also has responsibility for the care or treatment of the patient to enable him to look after the patient properly.

The test to be applied in such cases is to ascertain the nature or extent of that responsibility and thereafter to pass on any material information which will assist that person in fulfilling his duty. The mere fact that somebody cares for a patient will not entitle him to the entire record but only those parts which are relevant to his particular task.

Ultimately, ownership of records of any kind rests with the Secretary of State and possession by the legal custodian at a local level is governed by the normal duties which an agent owes his principal. The position is further complicated by the fact that although the physical record belongs to the minister the opinions belong to those making them. In other words they retain what amounts to the copyright. Accordingly if there is to be disclosure of any part of the record for a purpose other than the care or treatment of the patient it will be necessary to obtain the consent of: the owner (or his agent); the person whose opinion is being disclosed; and the patient.

In practice there are three reasons why hospital authorities are likely to be asked for information:

> Where a patient is, or may be, engaged in litigation with a third party and neither the authority nor its staff are directly involved.
>
> Where a patient or his representative is taking or contemplating proceedings (or making a claim) against an authority.
>
> Where a member of staff is taking or contemplating proceedings against the authority for an accident occurring in the course of employment.

If neither the hospital authority nor any member of hospital staff is a potential defendant in the proceedings and the report is required for the patient, the hospital authority should put no obstacle in the way of a solicitor who makes a written request, supported by his client's consent, for a report. Wherever possible one officer should be designated to deal with such requests rather than allowing solicitors to write to individual staff members.

On occasions it may happen that neither the hospital authority nor any member of the hospital staff is a potential defendant to proceedings, but the report is required on behalf of some person other than the patient (for example, the defendant); then the written consent of the patient must first be obtained. If his consent is withheld the solicitor acting for the other person will have to consider what further action to take, such as issuing a subpoena or an application for discovery.

The DHSS has said that in those cases when either the hospital authority or a member of the hospital staff is a potential defendant to proceedings, the hospital authority is expected to use its discretion in deciding whether to supply the report. In practical terms subject to legal guidance, the safest course to adopt in these cases is to refuse to disclose information. At this point the notes have become important not as an aid to the care and treatment of the patient but in their secondary function in an evidential role and the rules governing their use in this way are justifiably stringent.

The procedure was originally regulated by the Administration of Justice Act 1970. Prior to the enactment of this legislation no statutory provision had been made and questions of disclosure were dealt with on a voluntary basis, and the Act introduced new and extended powers by which the courts may order the disclosure of documents in and before actions and claims in respect of personal injuries or death.

Section 31 enables a person likely to be a party to subsequent High Court proceedings to seek an order from the High Court against a person also likely to be a party to the proceedings for disclosure of relevant documents before proceedings are commenced.

Section 32 enables a party to High Court proceedings to seek an order for production of documents, as above, but against a third party (not otherwise involved in the proceedings) and after proceedings have commenced. Notwithstanding these provisions, a further problem arose regarding the question of the person to whom disclosures should be made. Medical opinion has always been that it should be to another medical adviser only, while judicial opinion has, to say the least, been inconsistent. In the leading case of "Dunning v Board of Governors of the United Liverpool Hospitals (1973)" the Court of Appeal considered the application of Section 31 to medical records.

The Court took the view that the words 'likely to be made' in Section 31 of the Act referring to a potential claim could be construed as 'may well be made', and ordered disclosure to the applicants' medical adviser. In "Davidson v Lloyd Aircraft Services Ltd (1974)" an order for disclosure was made but confined to the medical advisers. Lord Denning justified this approach for the following reasons: records are difficult for the layman to interpret; they may be distressing to the patient; they may prove distressing or embarrassing to relatives; and the writer of any record should be secure in the knowledge that the contents would only be disclosed within the profession. This decision was subsequently confirmed in the later case of "Deistang v South West Metropolitan Regional Hospital Board (1975)". There the matter rested and it was thought that the law on this point could safely be regarded as settled.

However, in 1978 the case of "McIvor and Another v Southern Health and Social Services Board, Northern Ireland", the House of Lords ruled that 'the practice of the Court of Appeal in England under the Act of making orders confining the disclosure of hospital records, at any rate in the first instance to the applicant's medical adviser only, and not to the applicant, is contrary to the Act and decisions on that practice are wrong'. This striking reversal is unfortunately not quite as straightforward as it appears at first sight. In the course of his judgment, Lord Diplock stated that 'the legal adviser would take precautions to prevent information being known to a client' in appropriate cases and since only documents relevant to 'an issue arising out of the claim in the action' need to be disclosed 'any irrelevant parts of the document may be covered up'. Who, it is to be wondered, makes these decisions and edits the record? No doubt these matters will, in due course, receive judicial clarification.

In practice, this does not present insuperable difficulties; as long as the dominant intention of the request for information is for the purpose of litigation, or the principal purpose is for establishing a claim, many authorities produce records to medical advisers on the 'other side' on a voluntary basis, often in response to a draft affidavit justifying the request, without insisting upon obtaining a Court Order which is virtually automatic. Such an approach is clearly within the spirit of the 1970 Act, which sought to facilitate the negotiation of settlements before the trial and, if this does not prove possible, at least to enable both parties to proceed with full knowledge of the facts contained in the relevant documents.

Today the High Court has power to order production of such documents to the plaintiff and his legal and medical advisers, under Section 33(2)b of the Supreme Court Act 1981 and Order 24, Rule 7A of the Rules of the Supreme Court 1965.

On those rare occasions where it is decided not to supply information, a summons may be issued by the applicant supported by an affidavit setting out the reasons why the doctor or the hospital should be compelled to produce the specified documents. The existence of the power to apply for such an order does not mean there is an automatic right to disclosure, but authorities will wish at this point to consider whether they should release the information sought or, alternatively, to continue their refusal to disclose.

In the latter event a hearing date is fixed at which the court will hear the doctor or the hospital. They may argue about the justice or otherwise of the production of the records and seek any limitation as to the extent of the notes which are disclosed. Having heard the parties the court will, if it sees fit, make an order in the appropriate terms with which the authority must then comply.

Although, as we have seen, medical records are confidential, if they are relevant to legal proceedings they are not privileged (that is to say, no objection may be raised to their production) and a person in whose possession such documents were, would have to disclose them on the order of a court. Only if reports are made in the context of legal proceedings will they be priveleged, and this exception is made to enable parties to communicate freely in the course of an action without the fear that the opposition will know everything.

A P ANDREWS

22 May 1985

Mr Andrews made the following points whilst speaking to his paper at the symposium:

He reminded the meeting that his interest in clinical records was that of a lawyer. He saw a clinical record as having two possible roles: first and foremost, it is the clinician's working record, intended to facilitate the care and treatment of a particular patient; later, it may be required in an evidential capacity, to provide a detailed written account of what was done in the event of a claim for an alleged wrong being brought by or on behalf of a patient. Under current legislative provisions, such a claim must be brought either within three years of the alleged wrong, or within three years of the claimant having knowledge of the wrong. If a parent or guardian has failed to take action on behalf of a minor, the child may bring a claim for compensation within three years of attaining its majority; a former mental patient may do so within three years of 'permanent cure'. Moreover, the courts are able to extend the time limit in special circumstances. Thus, Mr Andrews argued, ideally every clinical record should be preserved indefinitely, as there is no way of foretelling when a claim may be brought. This would, of course, be quite impracticable.

In 1980, the DHSS issued recommendations for certain minimum retention periods for personal clinical records: for obstetric records, 25 years; for records relating to children, until the patient's 25th birthday or 8 years after the last entry, if longer; for records of the mentally disordered, until 20 years from the point at which no further care or treatment is considered necessary. Although in theory responsibility for the records lies with the Secretary of State, in practice it is delegated to the various health authorities; the 1980 circular stated that it is for those authorities to decide on actual periods of retention.

DISCUSSION PAPER B

What statistical information is available?

Dr M R Alderson
Chief Medical Statistician
Office of Population Censuses and Surveys

HOSPITAL CLINICAL RECORDS

WHAT STATISTICAL INFORMATION IS AVAILABLE?

This note begins with some background information, about the ideas that have been expressed in the past on the need for statistical information about individuals. It then turns to a discussion of the data that are presently available, and uses of the information, and ends by some comments about the likely trends in the future.

Background

Farr (1875) suggested that "The thing to aim at ultimately is a return of the cases of sickness in the civil population as complete as is now procured from the Army in England. It will be an invaluable contribution to therapeutics as well as to hygiene; for it will enable the therapeutist to determine the duration and fatality of all forms of disease under the several existing systems of treatment in the various sanitary and social conditions of the people. Illusions will be dispelled; quackery as completely as astrology suppressed; a science of therapeutics created; suffering diminished; life shielded from many dangers. The national returns of cases, and of causes of death will be an arsenal which the genius of English healers cannot fail to turn to account."

Despite this suggestion of principle, England only continued to collect mortality data, throughout the 19th century. Arrangements were made for the notification of infectious disease in the 1920s; no national system was established for recording episodes of hospitalisation, let alone disease treated by family practitioners until the end of the Second World War.

Stocks (1944), one of the successors of Farr, returned to discussion of this topic. Stocks emphasised that the conquest of acute diseases was likely to continue with increasing rapidity and that chronic degenerative diseases will assume a greater importance in the general morbidity picture. He suggested "the ultimate aim is to keep for every individual a record of every event of health significance from the time of conception to death, and to establish a system by means of which a person does not cease to exist statistically when he removes to another administrative area." He acknowledged that this was no new idea, but the administrative machinery was only now likely to be at hand, and a public opinion being educated to the point of being ready to welcome it.

Shortly after the end of the Second World War, with the advent of the NHS, arrangements were made to establish a system to collect particulars of patients having inpatient treatment in hospital. This was initially piloted in a few hospitals, and the original aim had been that the patient's name would be recorded, so that repeat admissions could be linked centrally in a record and statistical system. However, on grounds of confidentiality the medical profession and the Ministry of Health did not support the collection of named data. On financial grounds, the scheme that was launched in the 1950s only related to a ten per cent sample of hospital discharges.

Statistical information available today

This section discusses the statistical information available for England

and Wales, covering not only particulars about hospitalisation, but with a brief mention of other morbidity and mortality statistics relevant to analysis and interpretation of hospital data.

OPCS (formerly the General Register Office - GRO) assembled statistics on mortality, to which was added notification of infectious disease in the early part of the present century. About the time of the advent of the health service, cancer registration and hospital discharge statistics (HIPE) were added. There have been three major surveys collecting morbidity statistics from general practice (in the 1950s; around 1971; and around 1981). Following the thalidomide episode, arrangements were made to notify congenital malformations. The introduction of legislation on abortion was accompanied by the obligation for completion of a return to the Chief Medical Officers, for England and Wales, with OPCS taking responsibility for processing this. Since 1971, a General Household Survey has recorded limited particulars about hospital outpatient attendance and admission.

In considering the availability of information for the above topics one needs to consider (1) the published statistics, (2) the retention of computer files that can be accessed for further analyses, (3) the degree to which the original paper records have been retained by OPCS, and (4) whether name is available for the individual records and whether a name cross-index to the statistical material exists. This is set out in the attached table for each of the topics.

Because of the emphasis on the contribution of hospital records, it is appropriate to comment on the degree to which these different statistical sources relate to hospital care. At the present moment, well over 50 per cent of deaths occur in hospital, and the original records specify in writing the name of the hospital concerned. However, the individual hospitals are coded, but analyses are published only by category of hospital (for example, distinguishing NHS from non-NHS, and psychiatric from non-psychiatric). With judicious interpretation the statistics can however be utilised to identify institutions, as the place of death may have a unique coding for the registration particulars. Ad hoc studies are possible, and will be discussed below.

The statistics from HIPE relate to either non-psychiatric hospitals (distinguishing by a code whether these are acute, partially acute, or chronic) and maternity hospitals. The statistical system for psychiatric patients is presently incorporated in the Mental Health Enquiry, run by DHSS. (Material for patients in psychiatric hospitals had been handled by GRO in 1949-60, and from then on by the Ministry of Health, being merged in the Mental Health Enquiry in 1964.) Apart from these statistics on hospital inpatients, the data for notifications of abortion will distinguish those occurring in NHS premises and other locations. The cancer registrations will predominantly relate to patients that have had inpatient or outpatient diagnosis (there is a small proportion of patients who do not attend hospital, or who are diagnosed in private practice, for which records may be obtained following OPCS identification of the presence of cancer through death certification). The statistics on congenital malformation are a by-product of the birth notification system, initiated by the attendant at birth. The data relate to abnormalities at birth or within the first week of life identified by medical staff caring for the baby in hospital. Again, the material does not identify the specific hospitals concerned, nor does it identify any particulars about the care of the neonate.

The statistics from general practice include limited data about referral

to hospital, including direct access investigation, referral to outpatients, or referral to inpatients. However, this is a very limited aspect of the statistics, and the main topic covered is identification of the diagnostic labels applied to patients contacting their general practitioner during the period of the survey. The survey is based on volunteer general practices, with about a quarter million patients on their lists.

The notifications of infectious disease predominantly relate to relatively minor infectious disease, such as measles, which are numerically important and treated by general practitioners. The scheme does not distinguish whether hospital diagnosis has been achieved, let alone whether this is through direct access investigation, or referral of the patient to hospital. There are of course some infectious diseases where one would normally expect admission to be automatically achieved, and some analyses can be carried out on these (for example, the severer forms of meningitis, or the rare but very severe infectious diseases).

An important point to emphasise for all the data topics discussed so far is that the material is what is technically known as "event-based". The table at the end of these notes indicates the material for which an individual's name is available, and whether a cross-index is readily available. It will be seen that for HIPE the statistics and the original forms are not available with unique identifiers for the subjects - and therefore the aspirations of both Farr and Stocks have not been achieved so far as England and Wales are concerned. The material for mortality and cancer registrations are named, and with appropriate precautions ad hoc studies may be carried out utilising the name in achieving linkage or furthering extended enquiry based on these named data. It is important to emphasise that, though HIPE was planned to have name and be linkable for repeat admissions, this has only been achieved at regional level in the Oxford region (the Oxford Record Linkage Study has linked hospital discharge data with cancer registration and mortality from 1962 onwards - see Acheson, 1967). Very different is the scheme available in Scotland which does permit linkage between hospital discharge records, cancer registration, and mortality at national level (Heasman and Clarke, 1979).

The General Household Survey has recorded, since 1971, limited particulars about "contact" with hospital. The detailed general information about individuals and households can be analysed in relation to (a) outpatient attendance in the three months prior to interview, and (b) inpatient spells in the three months prior to interview 1971-76 and in the past year in 1982.

Other statistical systems

Event data are of limited value without population estimates. Since 1801 decennial censuses have occurred, apart from 1941. Such censuses permit mid-year estimates of population to be published by age, sex, and locality. In addition, more detailed information on demographic particulars is provided from census analyses (for example, giving details of occupation, household structure, housing, and so on).

Rather beyond the focus of the present meeting is the need to consider the availability of environmental or behavioural data for any analyses that attempt to associate "aetiological factors" with the development, progression, or mortality from specific diseases. This has been reviewed elsewhere (Alderson, 1983).

Current uses of the material

Event data can be utilised to examine distributions which are tabulated by the traditional axes of person, place and time. Thus the HIPE data may be examined to look at variation in discharge rates by sex and age and marital status; discharge rates by locality of the country; discharge rates for a given diagnosis over time. The two key items of medical interest within the HIPE statistics are diagnosis and operation; the system currently allows for up to six diagnoses and four operations to be coded. Rules are available for identifying the main condition treated and are being developed to identify the main operation performed. These data have been coded respectively to the ICD classification of disease (which identifies approximately 5,000 discrete diagnostic terms), and the OPCS operation code (which identifies 750 different operative procedures). However, many of the published tables use more restricted lists of diagnosis and operation in order to present tables that are not of excessive extent; the recent use of microfiche in the standard publications has permitted more extensive tabulation to be presented. However, there will always be more detail available, for additional ad hoc tables run on the computer file. Apart from diagnosis and operation, the other items of interest may be the specialty of care, whether the admission was emergency or from the waiting list, whether the subject was admitted from home or from some other institution, whether the patient was transferred from one specialty to another or from one hospital to another, and whether alive or dead on discharge.

It does not require emphasising that the amount of information that is stored in this statistical system is extremely limited compared with narrative clinical notes. The intention in the national scheme has always been to record the minimum that is feasible and yet would provide analyses of continuing interest at national level. The aim has not been the acquisition of detailed data potentially of interest to subsequent unplanned research. The important issue of the relative value of material (1) solely when collected for planned analysis, versus (2) the storage of detailed material which might subsequently be utilised for either data dredging, or planned ad hoc enquiry is beyond the remit of the present contribution. However, highly relevant to discussion of the extent of detail that warrants storage for future retrieval.

Future development of hospital statistics

The recommendations of the Körner Committee have led to activities which should result in a more extensive data file being available centrally than at the moment. The main differences with the file available from 1 April 1987 will be that this will cover 100 per cent of hospital discharges, it will cover newborn infants (the present system only includes a newborn infant if admission to a Special Care Baby Unit has been required), and OPCS will be handling data for all categories of hospital discharge, thus once more being responsible for material relating to psychiatric inpatients. However, though this will extend the computer files handles by OPCS, the material will still represent a minute part of the information available in clinical records, and the data available centrally will not permit linkage of repeat hospital admissions, nor the linkage of a particular hospital episode to information from other sources.

Dr Alderson made the following points while speaking to his paper at the symposium:

Any retention of records can be justified only if there is a clear understanding of the information which they can be expected to impart. Among the research uses for which clinical records may be required are historical studies, and Dr alderson suggested that historians may be content with a statistically biased sample, so long as the records which survive are detailed and legible. Another potential use is genetically-based studies, including those relating to past patterns of disease, or to groups of people given particular drugs or types of treatment. Such research has more sophisticated statistical requirements. Moreover, for any research, data must be not merely stored but made adequately accessible through a range of indexes: to names of patients, diagnoses, drugs used, treatments given and places of treatment.

In reply to a suggestion by Sir Richard Doll, that a 20-year retention period is sufficient for research needs, Dr Alderson maintained that, whilst this might be true for research on individual case histories, at least 30 or 40 years retention is desirable for more broadly-based studies.

He concluded by warning that, although the advent of cheaper and simpler computer systems might alleviate problems, this would not provide an instantaneous solution to questions of selection and storage of records worthy of long-term preservation.

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TABLE 1: AVAILABILITY OF NATIONAL STATISTICS RELEVANT TO HOSPITAL CARE HELD AT OPCS

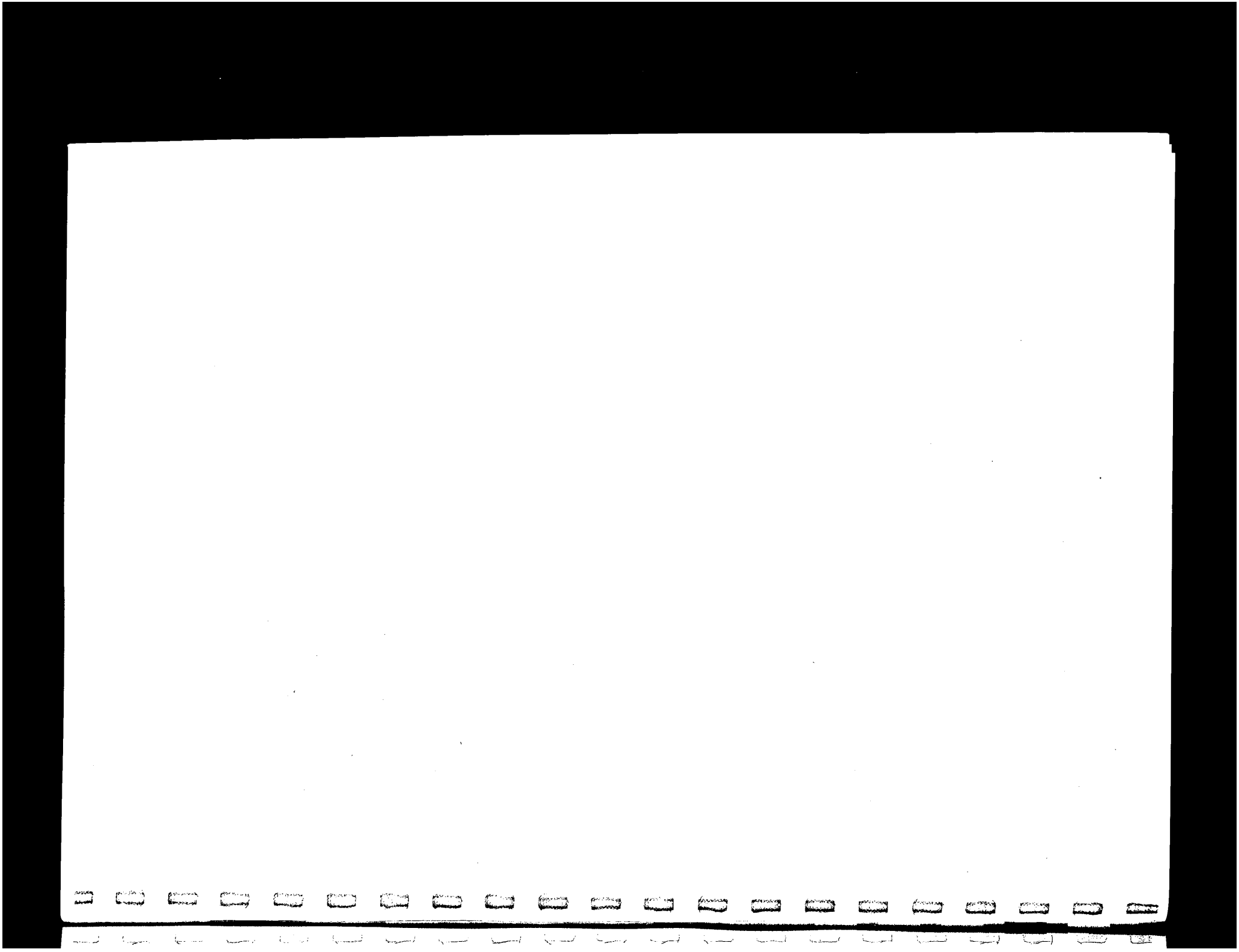
TOPIC	AVAILABILITY			
	Published Tables	Computer File	Original Forms	Name
MORTALITY	1838 -	1959 -	1838 -	Cross-index 1838 - Quarterly 1939 - Cumulative
ABORTION	1968* -	1969 -	Last three years	N.A.
CANCER REGISTRATION	1961 -	1961 -	1954 -	Cumulative
CONGENITAL MALFORMATIONS	1964 -	1964 -	1973 -	N.A.
HOSPITAL IN-PATIENT ENQUIRY	1949 -	1962 -	N.A.Ø	N.A.
PSYCHIATRIC IN-PATIENT	1949 -	1970 -	N.A.	N.A. **
MORBIDITY STATISTICS FROM GENERAL PRACTICE	1955-56 1970-71 1971-72 +	N.A. 1970 - 1971-72 1981-82	N.A. N.A. N.A. N.A.	N.A. N.A. N.A. N.A.
NOTIFICATIONS OF INFECTIOUS DISEASE	1922 -	1983 -	1946 -	N.A.

* 1968 - April to December

** To be erased under Data Protection Act

\+ In preparation

Ø The data are transmitted to OPCS by magnetic tape. Enquiry to RHAs indicates that the coded forms are destroyed after the computer edits have been carried out. The longest period of retention is six months in one region



DISCUSSION PAPER C

What records are kept now? The present scene

Mrs A Nicol
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and

Miss J G A Sheppard
Archivist
Contemporary Medical Archives Centre
The Wellcome Institute for the History of Medicine

The decision is unfortunately usually made hastily, sometimes by a junior member of staff, a porter, or even perhaps a builder needing to clear a site before demolition.

Finding a repository to take in this material is difficult. The idea of this symposium arose when we were approached by two different institutions. The National Heart Hospital had 900 ft of early clinical records and was about to move and had to dispose of its records. A temporary solution has been found at the PRO store at Hayes, but this is only temporary and unless somewhere can be found they will have to be destroyed. The other case was King's College Hospital, whose records from 1840-1937 had been placed in the Royal College of Physicians in batches from 1958. The Royal College was trying to deposit all hospital clinical records elsewhere and luckily King's College London now has an archivist who was able to accept them. (The other hospital clinical records at the RCP have yet to be placed.)

A similarly urgent situation faced Guy's Hospital some years ago and although the Guy's Hospital administrative and early clinical records are at the Greater London Record Office, the Wellcome Institute was urged to take in as a 'temporary measure', some 730 ft of Guys Hospital clinical records 1900-1930, and Evelina Hospital records 1870-1950, which they did.

Such solutions are not always possible however, and most local record offices do not normally take in clinical records. This is understandable.

Clinical records pose as many problems to archivists as they do to hospital administrators. The clinical record has not, traditionally, been viewed as worthy of permanent preservation by an archive. Administrative records (the minutes of the hospital governing body, committee papers, financial material etc) clearly need to be kept by the hospital for many years for its own efficient functioning. Archivists recognize that administrative records are essential documentary evidence, whereas patient records (with perhaps the exception of psychiatric records which have a more immediate appeal to the layman) are viewed as being created by and for the medical profession, with extremely limited value outside the practical reference for which they were created. The potential use of the material must be taken into consideration: whilst the administrative record will reflect local history, clinical records are not seen as being of particularly local interest (a point that can be argued against on the grounds of local epidemics, local famous names admitted to hospitals or indeed eventually genealogical research). Another difficulty over the use of the material posed to the archivist is that it is closed for 100 years except where specific approval is given to bona fide research.

Above all, archivists face the same problem of space shortage as the hospitals: few can take large deposits which will swamp their storage. Where exceptions have been made it has normally been for earlier case records where the other administrative records of the hospital have also been deposited. Even where the hospital has its own archivists the clinical records are normally considered not the concern of the hospital archivist but of the medical records officer.

Case files

As mentioned, comparatively little seems to survive of the inter-war case file, and the 'gap' between 1920-50 may to some extent be a reflection not only of the upheaval of the war but the reoganization following the setting up of the NHS.

These later files pose slightly different problems, of which bulk is the most important. The storage of these files leaves much to be desired: one London Hospital we visited had had a flood of sewage the previous week.

A brief indication of the size of the problem is gained by contemplation of a few statistics.

One West London teaching Hospital with 450 + beds reckons to create 20,000 new files a year. It microfilms when a file has been inactive for 7 years and reckons that it has 250,000 live files in its modern record store (excluding casualty). The size of a file varies enormously, but one could estimate approximately 25 to a linear foot. This hospital therefore now stores getting on for 2 miles of files.

To estimate how many case files are now being stored in this country is impossible. One can say that there are, very approximately, 400,000 hospital beds in the country, but no straightforward calculation of files can be made because of factors such as length of stay and the different policies adopted by hospitals with regard to their records. However one can be certain that the figure is very many miles.

The choice facing the medical records officer is therefore how to keep the records for as long as possible, (i.e. normally the recommended minimum legal term), and whether to microfilm.

We have tried to get some idea of the extent of microfilming in hospitals:-

Microfilming

On the whole general hospitals appear to follow the recommended periods of retention and destroy after the minimum period, although there is probably an increasing number which microfilm the records instead and keep the film, not the originals. It has incidentally been suggested that patient records from general hospitals are less interesting than those of teaching hospitals, and less likely to be of value to medical historians. Certainly specialist hospitals, such as the Marsden, have a reputation of good record keeping and place greater importance on the quality of the patient notes. Teaching hospitals clearly also place importance on the longer term use of the record, and this explains their tendency to microfilm. (We have incidentally been told that in fact very few consultants go back to older records for research.) A survey of hospital microfilming was undertaken by the Public Record Office last year with the help of Association of Medical Record Officers. It showed that the vast majority of teaching hospitals are filming and destroying originals. (The list attached shows the hospital filming done by one agency alone.) The age of the file when filmed varies from 2 to 15 years. Some hospitals have film going back many years

(e.g. Weston Park, Sheffield, back to 1928 and the Westminster Hospital, London back to 1923). There is apparently still strong resistance to filming by some hospitals, and many have kept their early volumes. Restrospective filming is costly and on the whole the filming dates back to no earlier than the 1940's.

Some specialist teaching hospitals have resisted microfilming and try to keep as much as possible. The National Hospital for Nervous Diseases for example keeps all in and out patient records. The Royal National Throat, Nose and Ear Hospital keeps all surgery and in-patient records. The Bethlem Royal and Maudsley Hospital has a set of patient records in excellent condition dating back to 1816 (although psychiatric records may be considered to have different criteria for selection or preservation).

It is worth noting that the microfilms appear to be kept for the most part in the working offices of the hospitals, and these are far from ideal conditions for the long term preservation of the film. If kept in ideal conditions (cool, dry, dark and secure) film will last for a long time (and that includes diazo film if not subjected to light). Some say there is no reason why it should not last forever, others would be more cautious and say 25-50 years. After this period a copy could be made but at each stage of copy there will be a slight loss of definition. A point made to us is that the quality of microfilming has improved since the 1950's when it started, and that some judgments against it are being made now based on the assessment of this early film.

What Survives?

The exact amount of clinical records (volumes, files and film) surviving in this country is hard to estimate, although a number of national and local surveys conducted by the Public Record Office, UMIST, the Contemporary Medical Archives Centre and elsewhere, give some indication of the extent to which clinical records exist in their original, pre-filmed state.

The localized surveys have normally been of all hospital records, and and not addressed themselves specifically to clinical records. Nevertheless, it may be worth noting them.

In 1980 the Contemporary Medical Archives Centre wrote to 79 repositories and of these 56 supplied detailed of hospital records and over 50% of the repositories know of relevant material elsewhere. A few record offices were exemplary, surveying and in some cases taking in hospital archives. The major problems were seen to be the bulk of the material, confidentiality aspects and sometimes on uncooperative attitude by the local hospital or local authority health administrators.

In 1981 the UMIST Survey covered some 238 local hospitals of which about 54 include details of case records. Only 10 of these are pre-1900 records and only one mentioned microfilming from 1935. It is likely however that since clinical records were not the specific interest of the project team, the hospitals did not necessarily disclose all the relevant information about their clinical records.

A questionnaire currently being produced by the Wellcome and Public Record Office on hospital records in general has so far been completed by the Greater London Record Office. Of the 105 London area hospitals mentioned in records held by the office, 73 include reference to patient (as opposed to clinical) records, the earliest being 1672 for St Thomas'. This includes admission and discharge registers, but it is worth bearing in mind that normally details of the reason for admission are included. Earliest clinical records tend to survive from the 1840's.

Survey work in hospitals in the NE/SE & SW Thames Region hospitals is also currently being conducted by Mrs. Barbara Craig from the Archives of Ontario. Her visits have confirmed that quite a large amount of records still survive in the hospitals, but usually in very bad condition. Of the 118 hospitals contacted so far 41 have placed their 'archives' i.e. nearly always administrative records the GLRO or another office, or have someone in charge of their historical records. 20 have not replied or have declined a visit. To date only on 36/118 is it possible to say something of the survival of the early clinical records. However this shows that an encouraging 20 out of 36 have kept them. This varies from long series such as Frien Hospital, 1851-1938, and Springfield (mental hospital) (from 1842) to odd amounts such as a set of surgeons case notes, 1890-1929, at the Royal Free. Examples on the destruction side show the Royal Homeopathic Hospital has only admission and discharge registers from 1948 and case files from 1962 and the National Temperance Hospital destroyed many recently after a flood.

St Bartholomew's Hospital demonstrates the peculiar state of the surviving clinical records: from 1826-40 they are fairly complete, from 1840-80 there are odd volumes, including some post mortem material, and these are mostly kept by disease. From 1880-1920 more orderly papers were produced which were bound by 'firm'. Only 1/8 of these survive (presumed sampled during 2nd World War paper salvage). From the 1920's individual case files were created and the complete series of files was kept until recently, when pressure of space led to the destruction of a great number. Consultants insisted that all files be kept for a minimum of 25 years after the last visit, and other than this only a minute proportion (2 files per annum) are being saved. Microfilm was investigated by the hospital in the 1960's and rejected, but is now being done internally for files from the 1950's onwards of patients not seen for 7 years.

The problem of what to do with clinical records is of course not confined to England and Wales

In Northern Ireland, the Public Record Office of Northern Ireland (PRONI) recently took in a large amount of case volumes and files from several hospitals on the understanding that the hospitals would review them and PRONI would keep the selected material. PRONI is now seeking to get this material transferred back to the hospitals in order to release much needed storage for records of more general historical interest.

In Scotland the problem has been recognised and as far back as 1966 the Western Infirmary in Glasgow looked into the matter of

selection. (See J.H. Mitchell, A New Look at Hospital Case Records (1969). More recently discussions have been taking place between the Scottish Home and Health Department and three regional health board archivists to try and work out proposals which could be recommended to the SHHD.

Further afield in Canada there are provincial as opposed to federal guidelines affecting hospitals. Psychiatric records are kept indefinitely, and 7/35 of these hospitals have placed records some dating back to the 1840's with the Archives of Ontario. Of the general hospitals a Public Hospitals Act and associated regulations against alienation of property has hampered deposit of material. Most of the larger teaching hospitals microfilm case records nowadays, and very few of those contacted have kept only clinical records.

In America more patient records seem to be kept and the patient appears to be more involved in the record keeping (possibly because of the legal and financial implications of poor record keeping and an unsatisfactory treatment). Indeed it is more usual for the patient to see his own record and the idea of the patient keeping his own record comes from the States. We have been told that American servicemen commonly photocopy their patient file when they leave the service. A survey of medical records retention policies in major teaching hospitals by the Johns Hopkins Archivist made the interesting observation that 'the smoothest running medical records progress (in terms of storage to retrieval) fall into two extremes:-

a) those hospitals which retain all hard copy records forever
b) those hospitals which routinely microfilm and destroy hard copy.

Problems arise where mixed policies operated because of difficulties in establishing criteria for retention/disposal and in implementing the policies.

ALEXANDRA NICOL
JULIA SHEPPARD

April 1985

Mrs Nicol and Miss Sheppard made the following points when speaking to their paper at the symposium:

Mrs Nicol recalled the inspiration for the symposium: requests from the National Heart Hospital and the Royal College of Physicians, for assistance with the appropriate disposal of holdings of clinical records, had demonstrated graphically the urgency of the problem and the danger of loss through indiscriminate destruction owing to desperate shortages of storage space. Referring to their (Nicol and Sheppard's) recent article in the British Medical Journal, she stressed that clinical records are still public records and must be dealt with systematically as such. The idea of a purpose-built medical records centre is superficially enticing, but begs the question whether so great a bulk of clinical records ought to be selected for permanent preservation.

Miss Sheppard explained that it is difficult to obtain statistics of clinical holdings. Most remain in hospitals, often stored unsuitably and inaccessibly, since they are not of primary daily concern to medical records officers. Nineteenth-century bound volumes of case notes may have a greater chance of survival, because of their sometimes attractive and durable bindings, than mid-twentieth century files. Survival is generally, however, a matter of chance, particularly when a hospital closes down. In London, for example, the Greater London Record Office has been unable to keep pace with the rate of hospital closures in recent years. Like most local record offices, GLRO prefers to concentrate on administrative records. The administrative records of Guy's Hospital and the Evelina Hospital are in GLRO's care; the clinical records have been given temporary housing at the Wellcome Institute's records store at Enfield.

APPENDIX

SOME HOSPITALS WHO USE THE SERVICES OF ONE AGENCY IN THE MIDLANDS MICROFILMING HOSPITAL MEDICAL RECORDS

LONDON

Croydon General Hospital
Children's Hospital, Sydenham Road
East Ham Memorial Hospital
Elizabeth Garrett Anderson Hospital
Guy's Hospital
Hammersmith Hospital
Harold Wood Hospital
Hither Green Hospital, Lewisham
Kings College Hospital
Mayday Hospital, Croydon
Middlesex Hospital
National Temperance Hospital
New Cross Hospital
Paddington Green Children's Hospital
Plaistow Hospital
Princess Louise Hospital, Kensington
Royal Dental Hospital, Leicester Square
Royal Homeopathic Hospital
Royal Marsden Hospital
Royal National Orthopaedic Hospital
Samaritan Hospital
South London Hospital
South Thames Cancer Registry
St. Andrew's Hospital, Newham
St. Bartholomew's Hospital
St. Charles Hospital
St. George's Hospital, Tooting
St. James' Hospital
St. Mary's Hospital, Harrow Road
St. Mary's Hospital, Newham
St. Mary's Hospital, Praed Street
St. Stephen's Hospital, Fulham Road
University College Hospital
West Middlesex Hospital
Western Ophthalmic Hospital

MIDLANDS

Birmingham Accident Hospital
Birmingham Immunisation Clinic
Central Out Patients, Stoke on Trent
City Hospital, Nottingham
Dudley Road Hospital, Birmingham
Forest Hospital, Mansfield
General Hospital, Mansfield
Groby Road Hospital, Leicester
King's Mill Hospital, Mansfield
Midland Centre for Neurosurgery and Neurology
Newark Hospital, Newark on Trent
Nuffield Hospital, Edgbaston
Royal Orthopaedic Hospital, Birmingham
Staffordshire General Infirmary
St. George's Hospital, Stafford
Trent Hospital, Stone
University College Hospital, Nottingham

EAST

Addenbrooke's Hospital, Cambridge
Great Yarmouth General Hospital
Lincoln County Hospital

S.W. and S.E. ENGLAND

Botleys Park Hospital, Chertsey
Goodmayes Hospital
Gosport War Memorial Hospital
Ottershaw Hospital
Queen Alexandra Hospital, Portsmouth
Queen Victoria Hospital, East Grinstead
Royal Berkshire Hospital, Reading
Royal Portsmouth Hospital
Royal Sussex County Hospital
St. Margaret's Hospital, Epping
St. Mary's Hospital, Portsmouth
St. Peter's Hospital, Chertsey

N.W. and N.E. ENGLAND

Alexandra Hospital, Cheadle
Barnsley District General Hospital
Burnley General Hospital
Chorley Hospital
Fazakerley Hospital, Liverpool
General Hospital, Warrington
Macclesfield Hospital
Oldham and District General Hospital
Queen's Park Hospital, Blackburn
Rochdale Infirmary
Royal Infirmary, Blackburn
Royal Infirmary, Huddersfield
Royal Liverpool Hospital
Scartho Road Hospital, Grimsby
Southport General Infirmary
Sunnyside Hospital, Southport
Victoria Hospital, Accrington
Walton Hospital, Liverpool
Withington Hospital, Manchester

WEST COUNTRY

Bristol Royal Infirmary
City Hospital, Truro
Redruth Hospital
Royal Cornwall Hospital, Truro
Southmead Hospital, Bristol
St. Austell Hospital
West Cornwall Hospital, Penzance
Weston General Hospital, Weston-Super-Mare

WALES

Bridgend General Hospital
C & A Hospital, Bangor
County Hospital, Griffithstown
Ebbw Vale Hospital
Glan Clwyd Hospital, Clwyd
Llandudno General Hospital
Maelor General Hospital, Wrexham
Nevill Hall Hospital, Abergavenny
Royal Gwent Hospital, Newport
South Pembroke Hospital
St. Cadoc's Hospital, Caerleon
St. David's Hospital, Bangor
St. Woolos Hospital, Newport
War Memorial Hospital, Wrexham
Withybush Hospital, Haverfordwest

SCOTLAND

Dundee Royal Infirmary
Ninewells Hospital, Dundee
Peel Hospital, Galashields
Raigmore Hospital, Inverness

DISCUSSION PAPER D

Explanation of the problem (1)

Miss W B Marshall
Formerly Patients Services/Planning Administrator
Addenbrooke's Hospital, Cambridge

Hospital Clinical Records - Explanation of the Problems (1)

(Contribution by Brenda Marshall to the Symposium on 8th May 1985)

I intend to talk about aspects of the most basic problems exercising the ingenuity and moral fibre of most records officers. Many other problems are more interesting and call for greater technical knowledge and more intellectual solutions, but the problems of records storage have to be grasped by us all. If they are not solved satisfactorily, there is no firm foundation on which more elaborate systems can be built.

All records officers are hampered by three 'ations', two of which are wholly beyond their control.

The first is a problem known to the entire population in one form or another - inflation. This affects the keeper of records in four major ways:

(a) Numerical. Of all the service departments in a hospital, only the records department has a snowball of material that grows so inexorably - at least, only the records department is expected to keep that material for so long. It would be difficult enough if the same number of records were created each year - 20,000 in 1982, 20,000 in 1983 and so on. When I went to Addenbrooke's Hosptial twenty years ago we opened opproximately 22,000 new folders each year - that is, a folder for every patient who had never attended hospital before. In 1984, the number of new folders was approximately 30,000 - and growing. So - if not quite an exponential growth - a higher number of folders will be created each year to be added to the existing folder population, much of which cannot be destroyed. This has implications for maintenance as well as for storage - it is hard enough to look for a set of missing notes in a population of 10,000 - how much longer may it take when that population has grown to 600,000.

(b) Even more significant is inflation within the individual folder. The following table illustrates this quite graphically. It describes the situation at Addenbrooke's Hospital in 1968 when a new records library was commissioned and in 1981 when a crisis was advancing rapidly:

Year	Capacity	Records stored
1968	a. Current library - 5,600 Shelf feet	15 years, with 25% of shelves empty
	b. Basement " - 7,000 " "	5 " " 85% " " "

What a halcyon situation - it compensated entirely for several months of laborious and tiring re-filing of hundreds of thousands of folders from two libraries in straight numerical order into two libraries constituted on quite a different basis in terminal digit order. 20 years' records took up a mere 6,500 linear feet of shelving.

But see how the situation had changed by 1981.

Year	Capacity	Records stored
1981	c. Current library - 5,600 shelf feet	4½ years, with no empty shelves
	d. Basement " - 7,000 " "	Almost full

Primarily because of the explosion of pathology reports (another 'ation' - computerisation which is usually regarded as the staunch aide to records officers - was the enemy on this occasion) records were by this time almost four times as thick as thirteen years previously. Some of the additional size was, of course, due to the continuing attendances of patients under the unit system - but pathology was the real culprit. What had looked very generous provision had quite quickly proved to be inadequate.

(c) Inflation reminds me that the actual weight of records should not be underestimated. One linear foot of folders weighs 35 lbs (and one linear foot of X-ray films weighs 72 lbs). It is no good, therefore, except in a basement with good foundations to rely on raising the height of the filing racks. Quite apart from the feelings of the filing clerks, who may not like to have to clamber up and down ladders all day, you may find a first floor library sinking through the floor. This situation threatened at Cambridge, despite the fact that the most careful weight statistics had been supplied at the planning stage - only at Addenbrooke's the records would have descended on top of physiotherapy patients, whose treatment area was sandwiched between the current (first floor) and basement libraries.

(d) In a hospital without the benefit of a computerised patient administration system, inflation of the master index can prove one of the most troublesome problems, both in relation to maintenance of good order and culling. Even indexes with a shorter life - Accident and Emergency department, or X-ray department for instance - need to be filed in a special way to ensure that the index does not eventually strangle the department or force the department to grind to a halt while the entire clerical staff weeds it.

The second problem entirely outside the control of the individual records officer is <u>legislation</u>. We have already heard the legal viewpoint. The practical implications of implementing the guidance contained in HC(80)7 are rather alarming for the records officer. Guidance on the preservation of the records of minors is relatively straightforward - but has considerable impact on the space problems already mentioned. There is also the problem of how to identify children's records, especially those created in A & E, in such a way that their identification for prolonged retention is made as easy as possible. Maternity hospitals who traditionally have tended to dispose of notes when the patient had not attended for the statutory period have a double problem, even if they create separate folders for each baby, in ensuring that all relevant information about the antenatal period is preserved for 25 years. More space, more clerical effort. Psychiatric hospitals possibly have the most difficult task of all, although their throughput is relatively low compared to the other hospitals. It is difficult to envisage

an easy way in which some doctor - hospital or community - is going to state categorically that a patient has recovered completely. In practice, one must probably keep the records of all psychiatric patients until they are known to have died or would have reached some arbitrary age (perhaps 99). Again, this poses a problem of space and labour - both in operating a much larger population of records and in culling them eventually.

This brings me to the third 'ation' - the only one in which the records officer can be expected to affect the situation favourably - location. Unfortunately, our profession has failed so signally over the years to make the correct impact that even the Best Buy hospitals tend to provide totally inadequate records storage. In the first version, indeed, the records library was shown as a small corridor type area through which staff had to walk to hang up their coats, and which was separated from much of the rest of the department by the A & E department. In East Anglia, at least, this situation was improved as each succeeding Best Buy was built. But location can make a tremendous difference not only to the economy with which a records department can be run but also to the service it can offer. Many service departments would like to be on the ground floor adjacent to the Out-patient department (where notes are most likely to be needed in a hurry) and the records department is no exception. Even if this is not possible, the records libraries should have some easy form of communication - hoist or pneumatic tube - to the Out-patient department at least. It may be appropriate at this point to stress that records library should always be the term used to describe the area - 'store' conveys an area that in no way reflects the importance or type of function of the records library, and may convey a completely misleading impression to an architect or administrator. The weight problem already described must not be an alibi for siting the current notes in the basement. And as increasing bulk of individual folders means fewer notes in the current library, it is important that the backup library is not situated five miles away nor even (as at a hospital in London at which I once worked) on the roof of an adjacent six-storey building. Yet another 'ation' - miniaturisation - may well be put forward as the solution to this problem. Studies have shown, over a number of years, that just over 90% of New Patients needing re-registration, i.e. patients with existing records who are attending a clinic for the first time in a new episode, have last attended the hospital within 10 years, 8% last attended between 11 and 20 years previously and 1½% between 21 and 25 years previously. If 1,000 New Patients are seen each week, more than 50% of whom will have attended the hospital before, it can clearly be seen that retrieval may be difficult unless location and form of storage are satisfactory.

These are just three problem 'ations' - common, I suspect, to most records officers. They are all capable of solution if those who allocate resources are willing to accord them the priority they deserve. Where a silk purse service is needed and demanded it is no good issuing sows' ears only with which to concoct it.

Miss Marshall made the following points when speaking to her paper at the symposium:

Addenbrooke's, a large provincial teaching hospital, had come to terms with the problem of storing clinical records in limited space. Miss Marshall spoke scathingly of centrally-issued guide lines for medical records officers

which suggested storage calculations based on the laughable 100 files per linear foot, recently updated to the still over-optimistic 25 files per linear foot.

In reviewing records policy, Addenbrooke's identified five constraints:

1 The need to retain notes for future treatment of the patient;

2 the need to retain notes for clinical research;

3 the need to retain notes to meet legal requirements;

4 the increasing pressure on filing space;

5 the cost of keeping records, whether in original form, culled or miniaturised.

Five major options were then considered:

a destruction of all records after the minimum retention period consistent with legal requirements;

b storage off the hospital site;

c installation or hire of a comprehensive microfilm system, which would allow total recall;

d culling records, to retain only key documents, in their original form;

e installation or hire of a modified microfilm system, to retain key documents only, on film.

Option a was discarded as inappropriate to the demands of a large teaching hospital and regional specialist centre.

Option b was set aside as administratively inconvenient, and expensive to to staff and maintain.

Option c proved impracticable on grounds of expense: even at 1981 prices, the system would have cost around £24,000 per annum to maintain.

Studies indicated that option d would require massive expenditure of effort for minimal saving of space.

Option e was recommended as the best compromise available. Regulations were then drawn up for microfilming key documents at an appropriate time after a patient had ceased attending. Key documents include inpatient summaries and all correspondence concerning the patient. The compromise has proved generally satisfactory, although at least one example can be cited where inpatient summaries do not preserve sufficient detail for clinical research on the finer points of a subject.

DISCUSSION PAPER E

Explanation of the problem (2)

Mr J Pepler
District Archivist
Tower Hamlets Health Authority

Hospital Clinical Records: an explanation of the problems (2)

Any view of this problem must inevitably be coloured by the writer's own experience, and so, in what follows, I have drawn heavily on what I have seen and learned in Tower Hamlets Health Authority. However, there are currently four hospitals in the District, each of a different type - teaching, psychiatric, local acute and geriatric - and each with different practices and methods with regard to the keeping of clinical records, so I feel that my experience is reasonably varied. The one problem common to them all is, of course, that of quantity: The London Hospital, despite an active microfilming programme, still has more than 500,000 sets of notes in paper form and generates approximately 40,000 new sets each year, while St Clement's, the smallest unit, with 145 beds, has files from the early 1930's, and has generated more than 20,000 sets since 1965. All the units have records, either on paper or microfilm, for at least the last 30 years, while the London has an apparently complete set of records from 1893.

At present, there appears to be very little demand for use of the older records for medical research purposes: although all medical records staff were familiar with requests for patients' notes from within the last ten or twenty years, none could recall more than two or three requests each year for older records. It may be reasonable to suppose that such levels of use for research are equal to the average for the whole country, if not above it, bearing in mind the presence of the London Hospital Medical College, which might be expected to act as a stimulus. Owing to the laws on confidentiality, there is, as yet, almost no evidence of "historical" research use. In effect, medical records staff are charged with responsibility for a huge mass of material of negligible value to them. Quite understandably, this charge ranks low in their order of priorities, as long as an un-wanted basement or storeroom can be found in which to put the records. The quality of these storage conditions is relatively unimportant, ranging from a damp basement to a disused gallery, (in no case reaching the standard necessary for the preservation of potential archive material) since speed of retrieval is not required and serious physical deterioration is not likely to take place until after the records have lost any administrative value.

A policy of microfilming clinical records was introduced in The London Hospital in the 1950s, and has subsequently been extended to Mile End Hospital. In theory, all notes are filmed eight years after they cease to be current, and then destroyed. This has certainly made radical savings in space, without which the storage problem would long since have become impossible: a chance survival of male and female medical (as opposed to surgical) case notes for 1937 extends to 32 volumes, or c.18 feet, and it is clear that at least another 10 volumes are missing. However, microfilming does produce some problems of its own. In the first place, it is no more than a change of medium, and not an answer to the basic question of whether the records need to be kept. Further, the technology of microfilm is subject to change and

development: while modern reader-printers are a very effective tool with recently-made films, they cannot be used with older films, made in the 1950's, without time-consuming conversion. Little is known about the quality of the film used in the early years, and since there are so few occasions on which they are examined, it is difficult to monitor any deterioration. It is also not a cheap process in absolute terms: the District's current budget for microfilming is c. £40,000 p.a. Finally, it must be remembered that the problem of space is reduced, not abolished: the case notes of The London Hospital and its various annexes, between 1893 and 1950 occupy nearly 7,500 reels of film, which need to be stored in a controlled environment, and further space is needed for readers and printers.

On whatever medium they are held, there can be no doubt that hospital clinical records represent an enormous body of data which may prove to be of value to future researchers. However, the critical factor which affects their value is not their physical condition - although they must obviously be in a legible state - but the quality of the indexes and other finding aids which are provided. Many medical records systems have no more than a simple nominal index, in some cases recording no more than name, address and record number, particularly for the period before the widespread adoption of the World Health Organisation's International Diagnostic Indexes from the 1960s onwards. This sort of basic index is usually reasonably adequate for the primary purpose of the system which is to identify and retrieve the notes of particular named individuals; but it is clearly a very crude tool for research purposes. It is dangerous to try to predict the areas of study for which medical records may be used in the future, but it is difficult to think of many such areas for which a nominal index would be an effective means of access: the only ones which occur readily to mind are studies involving particular families, or certain types of statistical samples. Even studies of particular localities would be difficult, while studies of particular medical conditions would be almost impossible except in the case of specialist hospitals. If, however, more sophisticated and flexible indexes exist, the value of the records themselves is greatly enhanced, although the actual content may be similar to that of another collection with poor, or even non-existent indexes. To illustrate the point we may consider the examples of St Clement's and The London Hospital. The former started as a City of London Board of Guardians Infirmary before transferring to the LCC in 1930, from which date the case notes survive. During the 1930s, the Hospital had a mental observation ward, before becoming exclusively a psychiatric unit in the 1960s. However a future student wishing to study the records of the mental observation ward would find his task complicated by the fact that the patient records are mixed in with those of patients in the general wards and served only by a nominal index. At The London Hospital, however, the situation is very different: for the period 1895 to 1935, there are large, folio indexes, one for medical and one for surgical cases for each year. Each volume consists of two parts: a simple alphabetical index of patients, recording name, age, registered number, physician or surgeon, dates of admission and discharge, result of case, and a page

reference to the second part of the index; this part is classified according to type of disease or condition, for medical cases, and type of operation or part of body for surgical cases. Each also includes a detailed list of lesser conditions or operations with an indication of the more general heading under which they are to be found. The entry for each patient includes considerable detail of the progress of their individual case. This form of index represents a very much more sophisticated means of access to the data, and opens up a wide range of possible avenues of research, which would be difficult if not impossible with the records of St Clement's. Indeed there would probably be instances in which The London Hospital's indexes are sufficiently detailed, without the need to look at the notes themselves. If the decision were made to select particular collections for permanent preservation, the quality of intellectual access must surely be a weighty factor.

Although it might be theoretically possible to construct such indexes retrospectively, at the present time I cannot imagine a situation in which such a daunting undertaking could be justified. Similar considerations would apply to stripping or weeding files retrospectively. Although it could be argued that since the Discharge Summary sheet (or local equivalent) is usually felt to be sufficient in response to requests for notes from other hospitals, "weeding" a large backlog of case notes would be a mammoth undertaking, and would also run the risk of throwing the baby out with the bath water, since such a summary represents the first step away from the "raw" data.

There are several possible solutions to the problem of clinical records, but whatever may be decided in particular cases, there are general points which should be borne in mind. If it is felt that particular records should be kept for historical research, it is important that they be identified as early as possible and that proper provision should be made for them. However it seems unreasonable to expect medical records officers to devote time and resources to looking after these records for, say, the whole 100 year period of their confidentiality, when such work does not contribute to the primary functions of their department. Ideally those records selected for preservation should be transferred from the medical records departments to some suitable repositary after a very much shorter period, perhaps 30 years. It is also desirable that clinical records should not be divorced from other hospital records; this is true both in principle, since they all form a part of the same archive, and practically, since other records, both complementary ones such as admission registers, and apparently unrelated administrative records, can contribute background information useful for the interpretation of the clinical records.

Jonathan Pepler
DISTRICT ARCHIVIST

TOWER HAMLETS HEALTH AUTHORITY

Mr Pepler made the following points when speaking to his paper at the symposium:

As an archivist, he works on the assumption that once a record comes into his care, all current use for treatment or for legal purposes ought to have ceased. For what purpose is such material to be preserved from that point onwards? The problem of predicting future research needs is exacerbated by the 100-years closure on clinical records, but their bulk is too great to permit indiscriminate retention as an alternative to irreversible decisions on selection and destruction. Nor is microfilming a real solution; it offers merely a change to a less unwieldy medium, not an answer to the question whether such records are truly worth keeping.

Moreover, there is also the matter of who is to hold those clinical records which are selected for permanent preservation. It is unreasonable to expect hard-pressed medical records officers to store for a century records which have no continuing current use; they would probably be forced to relegate the records to remote storage areas with environmental conditions highly unsuitable for archives. Selection, followed by proper provision of accommodation for clinical records, are urgent needs. One suggestion is that health authorities be required to appoint their own archivists.

DISCUSSION PAPER F

Problems of confidentiality

Dr M O'Donnell

PROBLEMS OF CONFIDENTIALITY (Dr Michael O'Donnell)

This paper attempts to describe the background against which doctors discuss the confidentiality of medical records.

THE CONFUSED WORLD OF MEDICAL ETHICS

Certainty

My father was a general practitioner and I grew up in the belief that the confidentiality of information that patients gave to their doctors was absolute, that no part of it could be revealed without the patient's permission.

In those days the British Medical Association (BMA) endorsed the principle of complete secrecy but allowed doctors one exception to the rule. They could warn any persons whom a patient might have infected with veneral disease. (The exception suggests more about "middle-class morality" in the first half of this century than does the rule.)

In 1952, the year I qualified as a doctor, the BMA Council, aware that, in exceptional circumstances, complete secrecy might endanger the welfare or indeed the lives of others, debated whether to modify its policy. The vote went decisively against change.

Why did doctors then feel so strongly about the need for absolute confidentiality? They often referred to it as a "sacred principle" but it would be unfair to say they invented it to enhance their priestly status.

It was essentially a practical rule. Doctors knew - and still know - that many patients can be helped only if they give their doctors information they would not want noised abroad; if doctors do not guarantee confidentiality, they may be denied that information.

Teenagers under stress, for instance, may turn to a doctor if they know that they can confide their anxieties and fears under conditions of absolute secrecy. For many, a doctor may be the only person in whom they are prepared to confide and for some, a confidential talk with a doctor may be the alternative to suicide.

Yet, though the rule was sacred, it was not treated with undue reverence. Doctors themselves needed someone to talk to and confidential information often bounced across the tables of hospital dining rooms and doctors' homes.

The reason I was so aware of the rule of confidentiality as a child was that it was extended to embrace the doctor's family. It was deeply engraved upon my conscience that we should never answer questions about my father's patients or pass on the stories - mostly comic, rarely tragic - which he occasionally shared with us, possibly because he needed to share the burden.

Uncertainty

Over the past 25 years, as medical care has become less a matter of the wielding of individual skill (and power) and more a team performance, professional attitudes to confidentiality have grown less rigid.

The debate about secrecy has become a matter of defining the point at which a doctor's responsibility as a citizen overrides the responsibility to an individual patient.

Every medical institution still endorses the principle of professional secrecy. The change has been in the definition of the exceptional circumstances in which professional confidence may be breached without the patient's consent.

The guidelines issued by the General Medical Council (GMC), as amended in 1984, state:

> "It is a doctor's duty to his patient ... strictly to observe the rule of professional secrecy by refraining from disclosing voluntarily to any third party information about a patient which he (the GMC still has a fondness for sexist prose) has learnt directly or indirectly in his professional capacity as a medical practitioner. The death of the patient does not absolve the doctor from this obligation."

The GMC defines the following exceptions to this rule:

> If patients or their legal advisers give valid written consent.
>
> Confidential information may be shared with other doctors caring for the patient. It may also be shared with other health care professionals who collaborate with the doctor in caring for the patient "to the extent that the doctor deems it necessary for the performance of their particular duties". The doctor is responsible for ensuring that "such individuals appreciate that the information is being imparted in strict professional confidence".
>
> "If in particular circumstances the doctor believes it undesirable on medical grounds to seek the patient's consent, information regarding the patient's health may sometimes be given in confidence to a close relative or person in a similar relationship to the patient."
>
> If a doctor thinks disclosure of information to a third party other than a relative would be in the patient's interest, he must make every effort to get the patient's permission. Only in exceptional circumstances can he disregard the patient's refusal.
>
> Information may be disclosed to satisfy a statutory requirement, such as notification of an infectious disease, ... or if a doctor is ordered to disclose information by a judge or presiding officer of a court.
>
> Rarely on the ground of public interest, such as a police investigation of a serious crime.
>
> For the purpose of a research project approved by a recognised ethical committee.

In november 1984, after a debate about the problems of confidentiality that faced medically qualified historians, the GMC added the following comment:

> "The extent to which disclosure of medical information after the death of a patient is regarded as improper will depend on a number of factors, for example: the nature of the information disclosed, the extent to which such information has already appeared in published material, the circumstances of the disclosure, including the period that has elapsed since the patient's death.
>
> "The Council feels unable to specify an interval of years to apply to all such cases, and a doctor who discloses such information without the consent of the patient or a surviving close relative of the patient may be required to justify his action."

These guidelines represent a consensus, though not necessarily a unanimous, view taken by the people who happened to be members of the GMC at the time.

The guidelines carry no moral authority and would not necessarily be accepted by all doctors. Indeed, many have declared that the principle of confidentiality is so much part of their concept of practising medicine that, far from accepting the GMC's exceptions, they would refuse to breach professional secrecy even if refusal brought them into conflict with the law and they ended up in jail.

For doctors who think the exceptions do not go far enough, the GMC backs its guidelines with a formidable sanction. Doctors who trespass beyond them can be called to justify their behaviour before a disciplinary tribunal.

And doctors whom that tribunal judges to be guilty of serious professional misconduct can have their registration cancelled. Loss of registration does not debar doctors from practising but prevents them from practising within the NHS and so from earning their living from medicine.

Other bodies, like the BMA, which is not a licensing body but more a medical trade association or trade union, also produce guidelines but none are backed by sanctions as formidable as those that can be enforced by the GMC.

Confusion

How do these consensus views evolve? Clearly the GMC, which is a statutory body, cannot advise doctors to break the law even though, on occasion, it might be in their patients' best interests to do so. (It is ironic that though the law can order a doctor to reveal a professional confidence, a lawyer who breached professional secrecy to serve the common good would be guilty of professional misconduct.)

The GMC also has to acknowledge changes in the law. When abortion became legal, it also, overnight, became ethically acceptable. And only last February the GMC had to modify its guidelines because of the ruling of the Gillick case (see below). If the Gillick ruling is overturned when it comes to appeal, the GMC may well modify its guidelines yet again.

Only a few of the GMC's guidelines, however, have been determined by the law, and some 14 years experience of attending meetings and committees that struggled to achieve consensus on points of medical ethics has persuaded me that my profession's views on ethical matters are most often shaped by a pragmatic response to publicised events or by medical fashion.

The pragmatic response is understandable because the practice of clinical medicine leans heavily on experience learned from individual cases. And medical fashion is largely determined, as it is in other hierarchical professions, by those who wield most power.

When, for instance, Lord Moran attracted public acrimony for revealing medical details in his book about Churchill, the BMA tied itself in semantic knots trying to sound disapproving without actually expelling the old boy. While the GMC, on which Moran had many a friend, made no public intervention.

It is arguable that if the public row had been over a book published by an obscure country general practitioner, the responses of BMA and GMC might have been reversed - though I doubt that the GMC would have temporised with semantics.

Not all of medical fashion is determined hierarchically. Responses to individual cases may be affected by a mood that within the profession is expressed as "there but for the grace of God ..." but is seen from without as doctors closing ranks.

In 1971, for instance, the GMC considered the case of Dr R J Browne, who had disclosed to a father that his 16 year old daughter had been prescribed an oral contraceptive by a clinic. The GMC decided that Dr Browne was not guilty of professional misconduct.

Yet last year, when Mrs Victoria Gillick sought to make it illegal for doctors to prescribe contraceptives to underage girls without their parents' consent, the GMC guideline (later modified when Mrs Gillick won her case) was that in the rare circumstances where a girl could not be persuaded to tell her parents, the doctor had to respect her request for confidentiality.

Sources of confusion

There are good reasons why doctors' views on ethics should have grown increasingly confused. Fewer doctors now share the same religious beliefs and, as medicine itself has developed as a pragmatic craft and shrugged off the trappings of a religion, so the old certainties have been subverted.

Doctors have to make ethical decisions as individuals, though they may later have to justify those decisions to their peers. Guidelines issued by medical institutions do not give them answers to specific problems but merely map out the arena in which the ethical debate can take place. No wise man came down a mountain clutching ethical rules for doctors engraven on stone.

The Hippocratic Oath, for instance, which many people think all doctors swear when they qualify (in truth, most doctors never see it, not to mention read it) is more a compendium of professional restrictive practices than an ethical guide.

On the subject of confidentiality it reads as though it emanated not from the island of Cos but from Delphi:

> "Whatever in connection with my professional practice, or not in connection with it, I see or hear, in the life of men which ought

not to be spoken of abroad, I will not divulge as reckoning that all should be kept secret."

In 1968, when the World Medical Association amended its modern rewriting of the Oath in the Declaration of Geneva, it removed some of the ambiguity:

"I will respect the secrets which are confided in me, even after the patient has died".

But that word "respect" still begs a lot of questions.

In modern codes, the need for secrecy is not disputed. The problem comes in defining the point where professional duty overrides the duty of a citizen.

The American Medical Association, like Hippocrates, solves the problem by using impressive but evasive language. It advises its members that a doctor:

"... may not reveal the confidences entrusted to him in the course of medical attendance, or the deficiencies he may observe in the character of his patients (presumably American medicine has developed a character deficiency test), unless he is required to do so by law or unless it becomes necessary in order to protect the welfare of the individual or the community".

The BMA is less enigmatic when it lists its five exceptions to the general principle of secrecy:

"1 The patient gives consent.

2 When it is undesirable on medical grounds to seek a patient's consent but it is in the patient's own interest that confidentiality should be broken.

3 The doctor's overriding duty to society.

4 For the purposes of medical research, when approved by a local clinical research ethical committee, or in the case of the National Cancer Registry by the Chairman of the BMA's Central Ethical Committee or his nominee.

5 When the information is required by due legal process."

I think most patients, who assume that the confidentiality of information they give to their doctors is total, would be alarmed if they knew about the latitude granted to their doctors by the BMA exceptions 2 and 3 and by the AMA's enigmatic phrase "protection of the welfare of the individual or the community".

And it may to an outsider smack of self interest that the BMA can be so specific when defining the needs of its own members who engage in research yet be so woolly when naming circumstances in which doctors may deprive individuals of the right to control the disclosure of information about themselves.

I suspect many doctors would be alarmed if they knew how often confidential information in hospital records can be, and is, disclosed

without the patient's consent - a metter that I assume will be covered in the paper by A P Andrews.

I hope that paper will also deal with the legal ownership of hospital records. Most hospital doctors think that while the paper and the ink are the property of the state - and the DHSS has claimed ownership on that basis - the state does not own the information written in the record. And ingenuous patients might think that the information, passed to the doctor in trust, still belongs to them and they should control its dissemination.

Yet it seems that the information belongs to nobody. The Home Office legal advice given to the Lindop committee went thus:

> "Information is the knowledge conveyed to the mind by a statement of fact, and is not therefore susceptible of ownership. Where the statement is contained in a document, or other object having physical existence, that object is capable of being owned like any other chattel; but there is no ownership in the knowledge (true or false) which the document can be used to convey."

- a position that may be rewarding, by which I mean profitable, to lawyers but is of little consolation to patients.

Seven years ago, the Lindop committee expressed alarm at the number of circumstances in which disclosure of information in hospital records takes place and, since then, the number has increased.

I myself have witnessed a hospital records officer, giving evidence before the GMC, offer us extracts from a patient's records brought into open court without permission of the patient or of the patient's doctor.

And, in 1980, during a Granada television programme on medical ethics, I sat alongside a senior hospital administrator who declared that, as custodian of the hospital's records on behalf of the secretary of state, he would, if he thought it might help in the detection of a serious crime, hand over a patient's records to the police. He would not, he said, seek the permission of the patient or of the doctor involved. Indeed he would tell neither patient nor doctor what he had done.

The public reaction to both incidents was of angry indignation. Most people believe that a doctor's consulting room is still protected by the complete secrecy offered by a priest's confessional. We cannot blame them for growing angry when they discover that it is not. It is, after all, their privacy that is being invaded. That public reaction is one that cannot be ignored in any discussion of access to medical records.

Whilst speaking to his paper during the symposium, Dr O'Donnell suggested that in the past members of the medical profession were certain that confidentiality was sacrosant. In recent years, it has become more negotiable. He wondered whether the GMC was prepared to agree to rather too many exceptions to confidentiality in respect of clinical records of patients who are still alive, while perhaps maintaining an excessively rigid stance over those relating to deceased persons. Doctors have a proprietorial interest in their notes: a doctor will tend to regard them as confidential to him, rather than as confidential to the patient concerned.

DISCUSSION PAPER G

Problems of bulk: how government departments cope

Mr M Roper
Records Administration Officer
Public Record Office

PROBLEMS OF BULK: HOW GOVERNMENT DEPARTMENTS COPE

Michael Roper
Records Administration Officer
Public Record Office

If hospital clinical records were the only type of case file which had to be considered for preservation within the public records system, it might not have been necessary to hold this symposium. Unfortunately they are only one (if perhaps the largest) of a vast number of types and series of case files which are created within government departments and other bodies subject to the Public Records Acts and as such they have to be considered within the wider context of the problem of dealing with what the Grigg Committee (Committee on Departmental Records: Report, Cmd. 9163, 1954) called "Particular Instance Papers" or PIPs and defined as "often very large groups of papers, the subject matter of which is the same, though each relating to a different person, body or place".

The number of PIPs created annually is unquantifiable. An estimate of the holdings of PIPs in fifteen major government departments made in 1979 suggested that over 4½ million feet were currently held in store and that annual creations were running at over 200,000 feet. A survey of the PIPs held in the Department of Health and Social Security (excluding NHS records) recently revealed that some 35-40 million PIPs in some 70 categories are held in the Department, mainly in local offices. They include about 20 million general benefit files and 8½ million supplementary benefit files. The Board of Inland Revenue estimates that there are about 2½ million linear feet of case files in its local offices. The Companies Registration Office holds just over 1 million live companies' files, to say nothing of the files of recently dissolved companies.

Problems in the Selection and Sampling of PIPs

The first problem, already referred to, is that of bulk. It is patently obvious that it is impracticable to preserve all PIPs. If even 10% of existing PIPs were selected for preservation, it would double the holdings of the Public Record Office (just under 450,000 feet) at a stroke. Selecting the same proportion of future creations of PIPs would have the effect of multiplying the average annual rate of accrual of records to the PRO (500,000 feet) by a factor of five.

Secondly, the PIPs currently available for review may not always be a representative "population" for statistical analysis. Disposal in the past under the authority of Destruction Schedules, made with the approval of Parliament under legislation applicable before 1959, of the Particular Instance Papers Committee which operated between 1957 and 1965 or of post-1958 disposal lists, and the vicissitudes of administrative change and extraneous events, such as enemy action in World War II, have resulted in the destruction of PIPs in certain categories or earlier than a certain date and made the survivors to that extent unrepresentative.

A third problem is that of control. It is very difficult to regulate effectively the selection and disposal of PIPs, because:

a) records are widely dispersed, from Whitehall to local offices, and the cost of bringing them together for review would be prohibitive, even if storage space were available to house them;

b) there is constant change in the variety and purpose of PIPs;

c) where records are accruing, the design and execution of selection strategies are difficult and can be further complicated by the wide dispersal of records between local offices;

d) in small offices storage space is scarce and current papers have priority; therefore, there are overriding administrative reasons for disposal at the earliest possible moment; and

e) local offices in particular are not staffed to take on records work in addition to their main functions and the application of disposal lists expressed in anything other than the simplest terms would require greater supervision and higher grade staff than are normally available.

A further problem is that of confidentiality. Even where PIPs are not "statute-barred", i.e. there is no absolute statutory prohibition on the release of the information which they contain, they are likely to contain information supplied in confidence or personally sensitive information about individuals. They are, therefore, likely to be unavailable for consultation until they are 50 or even 75 years old, except perhaps by a limited number of specialist researchers who have undertaken not to disclose or present in their reports information relating to any identifiable individual. It is, therefore, difficult to judge from the level of current use what the long term research value of PIPs is likely to be. The experience of the PRO in respect of the classes of PIPs which it already holds and which are available for consultation is that these have been used, if at all, mainly for genealogical research. Only a handful of major academic research projects have been undertaken on PIPs in the PRO.

The destruction of records worthy of permanent preservation is an irreversible act, while the cost of preserving records unworthy of permanent preservation is high and continuing. All selection procedures involve compromise between potential information needs and available resourses in terms of storage capacity and personnel. Because of the bulk of the records involved, the economic factors are more explicit in the selection of PIPs for preservation than in other forms of archival selection.

The disposal of Particular Instance Papers

The Grigg Committee recommended that most public records should pass through a system of first and second review to identify those worthy of permanent preservation. However, it proposed that a different system should apply to PIPs, namely the establishment of a Particular Instance Papers Committee to take a census of all PIPs in departments as a basis for a once and for all decision as to which should be preserved and in what quantity. By 1965 it was felt that the PIP Committee's work was coming to an end and remaining categories of PIPs identified in departments and new PIPs to be created in future were left to be dealt with by longer term procedures recommended by the Grigg Committee, i.e. by departments taking the advice of the PRO and using disposal lists to keep a proper check on the treatment of PIPs.

The Grigg Committee suggested that, because of "the frightening considerations of bulk", as a general principle only those PIPs should be kept which were capable of being reduced to a statistical sample. It also recommended that "no attempt should be made to keep in the PRO records which would not otherwise be preserved, solely because they contain information which might be useful for genealogical or biographical purposes". Consequently it has been the practice to reduce the bulk of the PIPs to a selection or sample, usually on the basis of disposal lists, and to destroy the vast majority.

Some past selections and samples have been criticised subsequently. Certainly the distinction between selection and a sample has not always been obvious to those making decisions; even where it has been, fairly crude sampling techniques have been used. Nevertheless the decisions have been taken on the basis of the best statistical advice available within Government and, where it has seemed appropriate, from outside.

Where PIPs have been preserved in the form of a selection, this selection has usually been made:

a) on historical grounds, e.g. because it relates to someone who was famous or infamous, cases which aroused a high level of interest at the time, or cases which relate to major historical events or record major scientific, technical or medical advances;

b) on administratrive grounds, i.e. because the cases serve as precedents for legal or administrative action;

c) as a representative selection, drawn to illustrate the procedures used in handling different types of business; or

d) a combination of any or all of the above.

Selection calls for a considerable amount of knowledge and expertise on the part of the person or persons undertaking the work.

Where sampling has been undertaken a variety of techniques has been employed:

a) random samples, using a random numbers table to ensure that each PIP has an equal chance of being selected for the sample;

b) serial or systematic samples, e.g. every 10th or 100th file;

c) areal samples, e.g. files for one or more 'typical' geographical area, type of institution, etc; and

d) time series samples, e.g. files for every 5th or 10th year.

Sometimes the techniques have been employed in combination, e.g. the serial (every 10th box taken by the PRO) and time series (every 10th year taken by the National Maritime Museum) samples of Registrar of General of Shipping and Seamen crewe lists.

Of the sampling techniques only the random and, to a lesser extent, the serial sample can be regarded as in any way adequate for statistical enquiries. However, the extent to which the PRO and departments can undertake sampling on anything but the simplest basis is limited by the availability of resources and the need to avoid delay in reducing the bulk of records no longer required for departmental purposes. This latter consideration may often prove paramount in determining whether or not time may be given for interested parties to seek assistance with staff and finance from outside resources, even where such assistance might be forthcoming.

Some commentators have suggested that the solution to the problem of bulk and the difficulties of selection or sampling which stem from this, is the conversion of the PIPs to a more compact medium. Microfilm has been especially promoted in this respect. It certainly reduces bulk, but experience has shown that if the microfilm is prepared to archival standards, the cost will be prohibitively expensive and probably greater than preserving the originals.

However, if microfilming to lower standards can be justified for current short-term use and it is regarded as acceptable that the microfilm may not last permanently, may include much ephemera and omit some material that is important, may not present the material in its proper order, and may not always be legible, then the preservation of such microfilm may be preferable to the preservation of nothing.

Similar considerations apply to machine-readable records, i.e. records in a medium (usually magnetic tape or magnetic disk) which can be read, interpreted and processed only by the aid of a computer. Retrospective conversion of data from textual records is prohibitively expensive except where there is an immediate benefit to be gained from research based on computer analysis on the data. However, where records have been created in a machine-readable form, their preservation in that form may be preferable to the preservation of the paper source documents or the paper output. Nevertheless, this is only to exchange one problem, that of bulk, for another, that of impermanence, for magnetic media are not regarded as having long-term archival permanence and the provision of suitable storage conditions and the regular re-copying of data imposes a large burden on available resources.

Mr Roper made the following points whilst speaking to his paper at the symposium:

He identified four options for dealing with the exceptional volume of hospital clinical records:

1 To preserve every file;

2 to destroy each file once it is no longer required for current use;

3 to keep the key papers from every file, weeding out those of no long-term value;

4 to microfilm the key papers from every file.

Option 1 is impracticable; option 2 is too drastic. Both options 3 and 4 would be impossible retrospectively: weeding every file would be excessively costly in both time and money. Some prospective application of either option might be possible for the future, by the nationwide introduction of structured case files in which papers are identified at creation as being of either long term or ephemeral significance.

Sampling or selection appear to be more fruitful approaches. Again, there are various possibilities. Sampling might take the form of:

a random sampling applied by every authority, nationwide;

b retention of every n^{th} file by every authority, nationwide.

Of these, b would be the more practicable.
Selection might be conducted on the basis of:

c a representative selection, to cover various types of disease and treatment;

d a selection of records of particular interest, such as those relating to famous or notorious persons;

e a selection of records relating to a cross-section of types of patient.

These, and especially c, would demand a very high level of knowledge and expertise from the selectors, who would be required, in addition, to predict and provide for future research demands. The adoption of a selection programme carries a high risk that the selection may prove ineffective in later years.

DISCUSSION PAPER H

Fact sheet (for afternoon discussion)

Mrs A Nicol
Liaison Officer
Public Record Office

and

Miss J G A Sheppard
Archivist
Contemporary Medical Archives Centre
The Wellcome Institute for the History of Medicine

SYMPOSIUM, WEDNESDAY 8 MAY
FACT SHEET FOR AFTERNOON DISCUSSION

In our article in the British Medical Journal 'Why keep hospital clinical records?' we identified five choices. They could be kept in their original format; they could be microfilmed; they could be sampled or selected; they could be destroyed; or they could be kept according to local initiative. To these two more options should be added. The records could be kept by the patients themselves; or rigorous file keeping would do much to solve the problem. This fact sheet examines each option setting out the arguments in favour of and against each option.

1. **Keep in original format**

Case notes were introduced in the inter-war years. Before then clinical records were in bound volumes.

i) Bound volumes

In favour

a) use for medical research
b) use for historical research
c) those earlier than 1858 should not be thrown away* and as this instruction was issued over 20 years ago should this date be made later?
d) there is a reluctance to throw away bound volumes, the binding usually being leather, although their condition varies

Against

e) bulk Although a few local record offices have taken volumes in, a large number still remains in hospitals. A handful of district health authorities have appointed archivists but in the great majority of cases the volumes are neglected unless a member of staff who happens to be interested keeps an eye on them. However, the real problem arises when the hospital can no longer spare the room for them, or closes down. To take but one example. The National Heart Hospital has 900 feet of records which it can no longer store. As a temporary expedient they have been stored at the Public Record Office's intermediate repository at Hayes. But if permanent accommodation is not found they will be destroyed. If they should be kept, where?

f) are they really useful for research?

* HM(61)73

1. Keep in original format - contd

ii) Modern case files

In favour

a) use for medical research
b) use for historical research
c) patient care (but this is covered by 2c, 4iii or 6 below)

Against

d) bulk. In 1983, in England, there were 1,100 hospitals with under a 100 beds, 384 hospitals with 100-249 beds, 234 hospitals with 250-499 beds, 184 hospitals with 500-999 beds, and 21 hospitals with 1000 beds and over. At a very rough calculation that means that there were probably just over 400,000 beds. A hospital with just over 450 beds reckons that it creates about 20,000 files a year. It is impossible to estimate how many hospital case files are being stored in this country but the figure must be very many miles.

e) cost. The cost of storage varies between London and elsewhere. Storage in London is estimated to cost nearly £5 a linear foot per annum. Outside London it is estimated to cost about £2 a linear foot per annum. Thus a hospital with just over 450 beds creating 20,000 files a year, storing 25 files to a linear foot, is creating 800 feet of files. In London this costs about £4000, elsewhere about £1600. The cost of keeping 250,000 files (a hospital with just over 450 beds which keeps files until they have not been active for seven years reckons to have about 250,000 files) is £50,000 in London, and £20,000 elsewhere each year. The cost throughout the country must be enormous. Archival storage is much more expensive. If material is worth permanently preserving it must be kept properly, this means securely, out of danger of flood, with adequate fire precautions and in the correct climatic conditions.

f) difficulty of gaining entry to the file for medical research. The files are indexed under patients' names. Unless the files are of a specialist hospital, for which the subject matter would be apparent, or there is a diagnostic index, they are of limited value for medical research (see 3h below)

g) given the unnecessary amount of information on the files are they really useful for research? (see 7 below).

2. Microfilm

In favour

a) use for medical research (provided microfilm lasts)
b) use for historical research (provided microfilm lasts)
c) patient care
d) no bulk problem so all the records could be kept
e) when the file is microfilmed the obvious ephemera are excluded
f) no danger of losing important papers

Against

g) cost

i) agency filming. A jacket of microfiche takes 40 pages so one jacket is enough for the great majority of patients. A competitive quotation is 31p per jacket. To microfilm 20,000 files would, therefore, cost £6200. Alternatively the files could be microfilmed for which a competitive quotation is £8.80 per 1000 exposures. The cost would vary. Thus if the number of exposures per patient were 40 the cost of filming 20,000 files would be £7400 if the number of exposures per patient were 25 the cost of filming 20,000 files would be £4,400.

ii) in house filming. It is difficult to be precise because there is the initial capital expenditure (purchase of equipment, estimated in one London hospital to have been £30,000-£40,000) and the main running expenditure is in staff time. There are too many imponderables to give meaningful figures. For example, staff costs may be kept down by employing someone only part time, but that is not making full use of the equipment.

iii) making copies for use. This is not, apparently, very common. The main expenditure would be purchase of equipment (a diazo duplicator costs about £10,000).

h) loss of some information e.g. light blue ink is often lost

i) difficulty of gaining entry to the files (see 1 iif above)

j) user resistance

k) quality will deteriorate over time unless kept in ideal conditions. Microfilm should be kept in a cool, dry atmosphere. Hospital clinical case microfilm seems generally to be kept in offices. (If paper is to be permanently preserved it should also be kept in the proper climatic conditions)

Query

l) should there be restrospective microfilming, either back to the introduction of modern case files, when these survive, or of bound volumes if no respository can be found for them?

3. Sample or Selection

How? A selection could always be sampled.

Sample

a) random
b) one in every n files
c) files opened on e.g. one day a year

Selection

d) files of certain geographic areas
e) files of certain hospitals e.g. teaching
f) files from different regions of hospitals of different kinds
g) files of interesting cases or people (who decides?)
h) files of specialist hospitals or of those which keep diagnostic indexes (see liif above)
i) select from file e.g. keep pnly the front page (the information available on the front page varies from hospital to hospital)

A sample or selection could be either of originals or microfilms.

i) Originals

In favour

a) some information would be kept for future research
b) if there were sufficiently small amount entry into it would be possible

Against

c) depending on how it was done it would be of limited use for medical research (historical research would be less affected as it should still be possible to follow themes such as social trends)
d) depending on how it was done it would not help patient care
e) unless the sample or selection was infinitesimal the problem of bulk and storage would remain
f) it could be time consuming to do

ii) Microfilms

In favour

a) as 3i a and b above
b) no space problem
c) the sample or selection could be copied onto e.g. diazo and preserved in archival conditions which would be impractical if all were preserved

Against

d) as 3i c and d and f above
e) user resistance

4. Destroyed

i) After keeping for recommended time for legal purposes

In favour

a) less problem with bulk

Against

b) little, if any, use for medical research
c) no use for historical research
d) it could adversly affect patitent care

ii) After keeping for longer e.g. 20 or 30 years

In favour

a) better for medical research
b) better for patient care

Against

c) little use for some medical research e.g. into hereditary diseases
d) very little use for historical research
e) problem of bulk unless microfilmed. Is it worth microfilming if it is going to be destroyed?

iii) Keep for patients' lifetime

The arguments are the same as in 4ii above, except that it would be excellent for patient care, but the problem of bulk would be much worse, unless there was microfilming. If this were to be really effective careful track would have to be kept of the file. With a mobile population a patient might attend several hospitals not necessarily within the same district or region.

5. Status Quo

In favour

a) some of the volumes which survive will be saved although some will be destroyed as policy or without thought
b) most of the teaching hospitals and some general hospitals are microfilming
c) some argue in favour of serendipity
d) it avoids the need for decision, although on the ground decisions will have to be made all the time

Against

e) some surving volumes will be destroyed
f) the microfilmed records are unlikely to survive permanently
g) decisions will be taken in an uninformed way. For example the basis of the selection might be the physical condition of the records.
h) it is avoiding responsibility

7. Better file keeping

It has been suggested that the problem would be solved if trivia did not clutter up the files. More vigorous file keeping is not, of course, necessarily an alternative to the options already discussed: it could usefully be done anyway. Is it an answer by itself?

In favour

a) bulk would be reduced therefore allowing more files to be kept which would benefit medical and historical research and patient care
b) easier to use and more efficient
c) not only might each file be improved but some form of centralisation might be considered which would make retrieval easier

Against

d) the scale of the problem is too great for this alone to be the answer
e) unenforceable. Recommendations would be made with no guarantee that they would be followed
f) this has been endlessly discussed but nothing has come of it

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6. Patients keep their own records

In favour

a) if they are not lost it is good for patient care
b) no space/cost problems
c) the basic information about the patient (name etc) would be checked and updated

Against

d) danger of patients losing files
e) the patient might adjust the record
f) the file might not be sufficiently informative
g) some files would inevitably find their way into archives but long term medical and historical research would be endangered