From Moore's Modern Methods to the World Wide Web: the evolution and current position of the Wellcome/National Archives Hospital Records Database

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I shall begin by locating the situation with British hospital records in historical context, as I don't know how much this audience knows about the evolution of the health care system in the UK and the status of its records. Up to 1948 when the National Health Service was inaugurated, there was an essentially quadripartite system of hospital provision. There were a large number of hospitals known as voluntary hospitals which had been established as philanthropic institutions dependent on the goodwill of subscribers and various forms of fundraising. Individuals wishing to obtain treatment for themselves or members of their family had to obtain a 'ticket' for admission from one of the subscribers. Some of the oldest and most distinguished hospitals and leading teaching hospitals in Britain originated in this way.

A separate system evolved from the obligations of the poor law system to provide medical treatment for paupers. At first this took place within workhouses, but increasingly dedicated infirmaries began to be built. There were significant constraints by place of residence and income on the patients they could accept. Local authorities were also permitted or obligated to provide various types of institution such as lunatic asylums. However, with the abolition of the poor law system in 1929, the way was opened for local authorities to develop and expand existing provisions into a municipal health service.

In addition, there were private hospitals and nursing homes for paying patients.

Military and naval hospitals were set up by the government for the treatment of regular members of the armed forces, plus a much larger number of temporary establishments were necessitated during two world wars.

In 1948 all voluntary and local authority (formerly poor law) hospitals became part of the National Health Service (but not private hospitals, and military and naval hospitals remain rather outside this system). As a result, their records, at least certain categories of them, are public records under the Public Records Act of 1958, as modified 1967. However, they form a class of records which may be held outside the Public Record Office, now the National Archives, in repositories approved by the Lord Chancellor. There have been a series of guidelines as to what should be retained, periods of retention, etc, most recently *Records management: NHS code of practice* of 5 Apr 2006 [slide 2]. In theory all managers with responsibility for current records should be aware of the provisions of this code of practice.

A large number of hospital records have been transferred to local record offices or university archives under these provisions, and several hospitals now have their own professional archivists. But many, many hospitals still either retain their records on site or dispose of them in an unsystematic and haphazard way. Frequently they fall under the aegis of a busy administrator with other concerns, or are in the care of a retired consultant, with no ongoing provision for their care or for research access. They are often stored in far from optimum environments, attics, basements, boiler rooms: this is a report on records of a leading provincial women's hospital [slide 3] in the late 1970s:

It is a terrible mess. There are very few, if any, decently bound volumes surviving. At some stage [the basement] has obviously become very wet, and some volumes look as though they had been burnt as well.

And these are some examples of storage [**slide 4**] – at least these items are on shelves and appear to be relatively dry, if not free from dust and dirt. This [**slide 5**] shows the detritus from a set of badly stored volumes of case records.

The Wellcome Library is <u>not</u> itself an approved place of deposit for hospital records and we do not ourselves acquire them, with a few exceptions. We have nearly thirty years

experience in thinking about hospital records, as Hosprec, the Hospital Records Database, has evolved and developed. Hosprec is still an ongoing project and there are many persisting problems to do with hospital records, their survival, their retention, and their use for research, as I think will become apparent in the course of this talk. But when we started there was no centrally collated information on the records of hospitals, even those in local record offices.

In 1979 the Wellcome Trust set up the Contemporary Medical Archives Centre out of a concern that many records relating to modern developments in medicine and health care were being lost. We soon realised that it was important not just to acquire material, but to identify, locate and survey material elsewhere. Hospital records were on our agenda from a very early stage, although it was never the intention that we should collect them. In the autumn of 1979 a Health Records Study Group was set up. This led to the hospital records register in its first embryonic form, with an initial focus on hospitals in the 4 Thames Regions of the NHS. But then we started adding information for the rest of the UK from various sources. And from that basis we wrote round to local record repositories in a mapping exercise to find out what they had beyond what they might already have reported to the Public Record Office or the Historical Manuscripts Commission, and also any information they might have about records of local hospitals which had not been transferred to their care. We had a very good response.

By early 1982 there were over 1000 entries in the Hospital Records Register, which at that point was in the form of slips of paper filed in Moore's Modern Methods binders [slide 6], arranged by locality, and by hospital name within town, which was not necessarily the ideal way for locating information from the researcher's point of view. Even then it was anticipated that eventually the information would be computerised to facilitate searches.

A major problem with records kept in hospitals is that there is no inbuilt commitment to their permanent preservation, and changes of management, quite apart from closures,

amalgamations, rebuilding, etc (of which we have seen so much over the past decades), can have very adverse consequences. Nor is there any obligation on the administrators to let us know what happens to archives: in theory they are supposed to keep the National Archives informed, since hospital archives are Public Records, but we find much more breach than observance. This has been an ongoing cause of concern: we have information in Hosprec about records reported at one time as surviving within particular institutions, but we cannot guarantee that this continues to be the case.

Back in the early 1980s, we were trying to get the message out generally about the need to preserve hospital records and what the issues were. Unfortunately, and this continues to be the case, there was far more concern and interest among archivists, researchers, and a handful of doctors and epidemiologists, than among the administrators who actually had immediate responsibility. In May 1985 a Symposium on Hospital Clinical Records was organised at the King's Fund Centre, which involved a carefully balanced group of clinicians, hospital administrators, historians, archivists, epidemiologists and representatives of relevant organisations.

The suggestions discussed by the small committee set up as a result make rather gloomy reading over 20 years later. The first point, for example, was to improve advice from the Department of Health to hospitals and custodians of records: subsequent experience suggests that the latter have other priorities and may not even be aware of their statutory obligations. The working party submitted comments respecting the revision of the existing circular on the 'Retention, Preservation and Destruction of Records: Responsibilities of Health Authorities under the Public Record Act' suggesting ways in which it could be made clearer and more forceful.

In 1986 a detailed questionnaire about hospital records for distribution to local record offices was hammered out between the Wellcome archivists and the Public Record Office

Liaison Officer. With some fairly minor changes, this remains the basis for the information fields in Hosprec today. These consist of:

## On hospital [slide 7]:

- Names and previous names of hospital
- Current and previous addresses.
- When founded, if closed, when closed

## [slide 8]

- Associated institutions
- NHS Management bodies since 1948 i.e.
- 1948-76 Regional Hospital Board/Hospital Management Committee
- 1974-82 Regional Health Authority/District Health Authority
- 1982-96 The same, but there were various changes in 1982 due to local government reorganisation
- Trust, present and past
- County, before 1974, 1974-96, and present

The periods reflect various changes in health service or local government administration or structure

## [slide 9]

Hospital status

Pre-1948: Voluntary, i.e. philanthropic, supported by subscribers; Poor Law Infirmary;

Private; Local authority; Military or Naval; Other

Post-1948: NHS; Private; Trust; Military or Naval; Other

Hospital type:

Pre-1948: General, isolation, maternity, mental, tuberculosis, women, children and other;

Post-1948: Acute, geriatric, Maternity, Mental, Hospice and other.

• There is also a free text field where additional information can be entered

## Records [slide 10]:

- Where held
- Administrative, with start and finish dates: General administration; financial, estates and endowments, nursing, staff, admission and discharge; ephemera, pictorial, private papers, other.
- Clinical patient records
- Space for further information

National Archives website for the most up to date details.

Where finding aids are (this is much less necessary since the advent of the Web)
 Repository information. we now try and encourage online users to check ARCHON on the

This questionnaire was distributed, with the backing of the Society of Archivists and the Association of County Archivists, to local authority and other repositories known to be holding hospital records. The King's Fund Centre generously supplied funding to employ a project researcher, to check the questionnaires, fill in missing information, and input the data into DBaseIII software.

Stage 2 of the data-gathering exercise, to ascertain in more detail what was still held by hospitals themselves, initially in the Greater London region, by sending out a simplified questionnaire form, was disappointing. Seventeen Health Districts and around 91 individual hospitals in the Thames Health Regions were contacted. Only about a third of the hospitals knew what pre-NHS records were held, and this was because either they were held centrally or a long-standing staff member took an interest. In other cases the records were scattered or had been forgotten, and some hospitals were unable to provide any answer. It was very apparent that many administrators were completely ignorant of their legal obligations towards hospital records. This situation has not substantially changed, in spite of our hopes.

The closure of hospitals, especially psychiatric hospitals, as a result of health services reorganisation and changes in the direction of health policy, and the consequent loss of their records, became an increasing concern for archivists and researchers. The Health Authority Archivists Group was monitoring the situation, and decided to produce some guidelines to supplement the government circular. With King's Fund Centre support, this resulted in the booklet by Hamish Maxwell-Stewart, Julia Sheppard and Geoffrey Yeo, *Hospital Patient Case Records: A Guide to their Retention and Disposal*, published in 1996. This is now [slide 11] the Society of Archivists Best Practice Guideline 8 *After the hundred year rule Guidance for archivists and records managers on access to medical records under the Freedom of Information Act* by Colin Gale and Catherine Redfern and is available online.

During the 1990s Hosprec underwent various software migrations and upgrades with their concomitant problems. We were receiving increasing numbers of queries about hospital records, and researchers were occasionally given access to the database onsite in those pre-Web days. By the mid 1990s the number of entries was well over 2000.

In 1997 a simple user friendly front end enabled readers to query the database directly on the basic search fields of name and town from a terminal within the Library. More complex searches still had to be done by the archive staff. Hardly had we achieved this than the new frontier became the World Wide Web and we had to start thinking about mounting the database on the web for online access. Early in 1999, we sent out a mailshot to all repositories known to be holding hospital records, requesting them to update existing entries and complete data-entry forms for new accessions. These were all checked and research to improve the existing background information incorporated. At the conclusion, the database included information on records of nearly 2800 hospitals in over 1600 repositories.

At the beginning of 2000 Hosprec finally went online, hosted on the Public Record Office server. The presence of the database in cyberspace did not stop enquiries coming to us,

in fact these have noticeably increased. Most of these are not what we anticipated when we provided contact details for further queries (we expected a demand for more complex searches than the online version could accommodate) – they tend to be 'can't find X hospital, where are its records?' (if it's not there, we don't know), 'X hospital is there, but doesn't have patient records, where are these?' (probably destroyed). We even get queries for records of hospitals outside the UK. As health care systems, the legal position of medical records, and archival institutions vary so widely from country to country, we have no current plans to extend Hosprec internationally, although we have had some preliminary discussions with the National Archives of Ireland.

What are the uses of Hosprec:

- For researchers:
- 1. to locate records of specific hospitals
- 2. to identify particular kinds of hospital/hospital record

At present the first is possible via the online interface, which provides for simple searches by name (present and previous) or town [slide 12] – a search produces a summary hitlist [slide 13], with a link to the detailed entry [slides 14 and 15], within which there is a link to current contact details of the repository in ARCHON [slide 16]

In the second case Archives and Manuscripts staff at the Wellcome Library are prepared to undertake criteria searches (e.g. admission and discharge registers of public lunatic asylums for the period 1850-1914) [slides 17, 18], to provide a summary hit-list [slide 19] from which further details [slide 20] can be located using the online version and searching under hospital name.

• We also anticipated that Hosprec would also have use for archivists:

Firstly, to identify where surviving records of a hospital already are, when offered material

Secondly, to assist in decision-making about whether to take in (or to establish selection criteria for) records of a particular hospital

In the first case Hosprec is useful when someone turns up with strayed hospital records, which ideally should be reunited with any other surviving records. In the second instance, archivists could use Hosprec to establish how significant the records of a particular hospital might be – was it a type of hospital for which records survive very sparsely? Was it the only hospital of its kind serving a particular region? Does it have unusually full records of a particular type? Or alternatively, was it a fairly run of the mill institution in a well-served area?

At the moment, while the National Archives hosts Hosprec, maintenance and updating of actual data is done by the Wellcome. We are very dependent on repositories letting us know about new and additional accessions, listing, etc: we do not expect that the holding repository will necessarily be able to fill in all the database fields as many can only be completed from reference works in the Wellcome Library. A current project is to include fuller lists via a link via A2A in the online version [slide 21].

When a project evolves over so many years there are going to be problems – technical issues due to the series of software changes; information that's no longer current; decisions taken at one point in the light of available resources and information that might not be the way we would want to do things now.

On hospital records generally, over the years we have identified three particularly problematic issues. The first is the ongoing lack of interest in the non-current records of institutions among administrators who have immediate responsibility for them – and I would argue that the problems that arise due to closures, amalgamations, etc, can largely be put down to the fact that administrators are not aware of the status of the records they hold as public records, or of their legal obligations towards them.

The second and third problems are closely related. The bulk of hospital records is ever-expanding, especially with clinical notes. Lack of good records management practice during course of records' life-cycle contributes significantly towards bloat. Hospital records also contain potentially sensitive data, not only in clinical casenotes but in admission and discharge registers and even committee minutes, and therefore repositories need to ensure compliance with relevant legislation. These two problems are linked since many archivists are understandably reluctant to commit themselves to taking in bulky amounts which are also subject to stringent limitations on access. While the needs of historians, epidemiologists and social scientists might well be accommodated through some form of statistically valid sampling, I'm very aware, from the enquiries we receive, that there is a great deal of interest in hospital records from genealogists and family historians, who would presumably be unlikely to find sampling acceptable. I should perhaps mention that hospital records have benefited from some recent funding initiatives aimed at improving access to the UK's rich archival heritage: for example the Wellcome Trust's Research Resources in Medical History scheme [slide 22] has funded the cataloguing of the records of several significant hospitals, and the City and Hackney Hospitals Cataloguing Project at St Bartholomew's Hospital has been awarded a substantial sum by the Pilgrim Trust/Esmee Fairbairn Cataloguing Grants Project.

However, to finish on a more upbeat note, I don't think there's anything comparable to Hosprec in any other country. This is partly because of the legal status of hospital records as public records in the UK, but also has a lot to do with the network of local record offices and the tradition of archive-keeping. Visitors from other countries have been very impressed not merely by the effort involved in creating Hosprec but by the actual survival and availability for research of such a relatively huge quantity of records of hospital care, even if specific gaps are frustrating.