SOME PROBLEMS IN PLACING MODERN MEDICAL RECORDS IN PUBLIC ARCHIVES

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This article considers some ethical, legal and practical aspects of placing modern hospital medical records in a public archival facility with the intention of making them available for public access seventy-five years after date of last contact of the patient with the hospital, or sooner under certain specified circumstances. The initial problem of confidentiality is discussed then methods of reducing the volume of patient files are considered. Other appraisal considerations are briefly mentioned.

The Victorian Context

In Victoria, the General Disposal Schedule for Public Hospital Patient Information Records was issued in 1987.¹ It replaced a much shorter Schedule issued in 1980.² Research when preparing the new General Disposal Schedule (GDS) could not discover any document of a similar degree of detail, covering as it does most of the varied types of information related to patients kept by hospitals. The new GDS was prepared by Sue McKemmish of the Public Record Office Victoria (PRO) and myself; it was Sue's archival expertise and courage (in designating a class of patient records for permanent retention) that produced a Schedule which seems to be receiving acceptance in Victoria and interest elsewhere.

The new GDS does not apply to pre-1950 records which must be appraised by the PRO before disposal (transfer or destruction); nineteenth century records are likely to be required for retention in their entirety. For the post-1949 records, the GDS specifies eventual transfer to the PRO of all the major registers and indexes ("when references ceases") and a one-in-one-thousand serial sample of individual patient files. Apart from this sample, patient files are generally sentenced for destruction fifteen years after the patient's last attendance (longer for the records of children, less for those of deceased patients). Of the other types of patient information held in a hospital, patient-related records held in the Pharmacy Department are for destruction after three years (as specified by Regulations³). Patient-related records in the Pathology Department have varied retention periods as designated by the National Pathology Accreditation Advisory Council.⁴ Diagnostic imaging records and radiographic films are to be retained for five years. The butts of statutory notifications (births, deaths, notifiable diseases) are retained for one year. Microform records are specially sentenced. Preparation of the GDS is described elsewhere.⁵

Patient files are a type of particular instance file or case file and, in common with many other such files, are covered, during their active life, by rules regarding confidentiality. For this reason, they raise special problems for the archivist apart from their bulk and any difficulty of adapting finding aids created during the files' active life.

This paper considers some ethical, legal and practical aspects of placing hospital medical records in a public archival facility with the intention of making them available for public access seventy-five years after date of last contact of the patient with the hospital, or sooner under circumstances described below. This is considered in the Victorian context although many aspects would be relevant to other Australian States and to other countries.

There are some generally agreed exceptions to the rule of confidentiality for medical records. The procedure of placing such records in an archives is assessed against these exceptions as a measure of the justification for breaching confidentiality.

Having established that this break can be justified, it is necessary to consider the volume of patient files and how to achieve some reduction of the whole, in the hope that what is retained will be of value to future users. Some options are discussed and reasons given for choosing the method suggested in the GDS. The problem of volume is limited mainly to the patient files: the other types of medical information of long-term interest are manageable, being registers and indexes.

Some other appraisal considerations for patient records are briefly mentioned.

Confidentiality

In Australia, confidentiality of health information is not guaranteed in any statute although there have been cases establishing "a degree of protection from invasions of 'information privacy interests'".⁶ Such cases, even where not of Australian courts, can set precedents accepted by Australian courts. For example, in *Furniss* v. *Fitchett*⁷ a woman was awarded damages by a New Zealand court for the shock she suffered when a document (written by her doctor and given to her husband) was produced at a hearing for marital separation; the doctor was found to have failed in his duty of care.

While no statutes in Australia guarantee confidentiality, there are some which set penalties for anyone releasing health information in inappropriate circumstances but these generally apply only to staff of the health care institution.⁸

In Victorian public hospitals, patient records are owned by the hospital and therefore the hospital is responsible for protecting confidentiality.⁹ *Information* contained in the record cannot be owned by anyone "as no Western legal system recognises ownership of information as a separate legal concept, distinct from ownershop of the document containing it".¹⁰ Doctors also claim responsibility for confidentiality.¹¹ How such a responsibility can be shared, practically and ethically, during active life of records is a subject of debate.¹² For practical purposes, at the point at which records are eligible for transfer, responsibility for confidentiality must lie with the hospital.

The record writer, record owner, other employees of the record owner and third parties to whom information has been officially provided all have an obligation to maintain confidentiality; there is no such obligation on a person who acquires information unofficially (say, by overhearing a conversation or by reading a record left lying on a desk) because that person has no ethical or legal duty to the patient. Such a person, though, could be sued for defamation.¹³ However, by the time the records are available for public access, the risk of the researcher being sued will almost certainly have been removed by the seventy-five year closure period. The youngest a record subject could be is seventy-five years old (where the record is for a patient who was a new-born baby at the time the record was last used for patient care); most patients would be no longer living seventy-five years after their last contact with a particular hospital.

The obligation to treat medical information, documented and undocumented, as confidential is not absolute. There are a limited number of instances when it is generally accepted as ethical to release medical information: with the patient's consent, when the law requires it, when it is in the patient's interest, or when duty to society overrides the duty to the patient.¹⁴

The British Medical Association cites a fifth ground: for the purposes of medical research when approved by an ethics committee.¹⁵ Research can be considered under the heading of duty to society.

The first instance, released with the patient's consent, includes express and implied consent. Consent to a limited release of information can be said to be implied when a patient is admitted to hospital: the patient realises, for example, the notes made by the doctor will be read by nursing staff. Express consent is where the patient, verbally or in writing, consents to the transfer of information.

The second instance, release when the law requires it, includes by subpoena and under laws which require reporting (see, for example, the Victorian *Health Services Act*¹⁶ and Burton¹⁷). An example is the Medical Certificate of Death form which states the disease or condition leading to death and other conditions underlying or contributing to death; it is relevant to note that this medical information is available to the public without any closure period, raising the question that the right of the individual to privacy regarding health information may cease on death or at least start to diminish. Havard suggests this needs clarification¹⁸ while Kottow argues that death "does not cancel the obligation of confidentiality which remains of import to all survivors within the radius of interests of the deceased".¹⁹

One example of the third instance, release where it may be in the patient's interest, is now defined in the Victorian *Health Services Act*: a doctor does not breach confidentiality by giving information to the patient's next of kin "in accordance with the recognised customs of medical practice" 20

The last instance, an overriding duty to society, is very difficult to define. Texts for doctors give examples of appropriate situations (for example, Burton²¹ and Green²²). The Victorian *Health Services Act* permits it when it is, in the Health Minister's opinion, "in the public interest that the information be given".²³ The Minister receives no help from the Act in deciding what the public interest might be.

Placing medical records in a public archives is to breach confidentiality. The following assesses whether this breach can be justified under any of the exceptions described above.

It cannot be said that patients give *implied* consent to record transfer as this transfer procedure only started in 1988 with records of patients last treated fifteen years ago. If *express* consent were to be obtained, should *all* patients be asked or only those whose records are to be retained (supposing this were predictable at creation, as is the case in the GDS's suggested method)? And at what time should the request be made? If only *some* patients are to be asked for permission, a patient might suspect a sinister reason *his* record was wanted for permanent retention when he knows others have not been so informed. To ask *all* patients would be to increase the work a thousandfold. The occasion of admission to hospital could also be an inopportune moment to make such a request: the individual may be in a less than favourable frame of mind.

For existing records, if the person were re-admitted, permission for transfer could be sought then; if there were no further admissions, a letter would have to be sent when or before the record became eligible for transfer. Many patients would no longer be at the last known address and mailing would incur much effort and cost. For selection methods that do not identify a record as permanent at creation, a letter would also be required once the record is identified as permanent.

Patients often assume medical records are kept indefinitely. Hospitals, the Health Department Victoria (HDV) and the PRO receive numerous enquiries from members of the public about the location of old records; enquirers can be distressed to hear that records have been destroyed. Such individuals would clearly be in favour of permanent retention, although this favour may not extend to public access, even after the long closure period. Many people are not reticent about discussing their own health problems; however, this characteristic in some individuals cannot be extended to imply consent from all individuals for transfer.

The second ground for release is, where the law requires it. Because a public hospital is a "public office" according to the Victorian *Public Records* Act^{24} and because the GDS is issued in accordance with the Act^{25} , there is a clear legal obligation for hospitals to transfer records.

The third ground for release, that of the patient's best interest, would apply if enough patients benefitted significantly from the availability of the record for the lifetime of the patient (instead of the present fifteen years after last attendance). If this were the justification for the permanent class, *every* record should be retained: clearly beyond the capabilities of hospitals and the PRO.

The fourth ground for release, where duty to society overrides duty to the patient, may have some relevance. As has been noted, death certificates are already available and dead people cannot be defamed, thus duty to the patient might have completely disappeared by the end of the closure period. (For *doctors*, however, publishing information about deceased patients is still frowned on whether the information was obtained during the doctor's clinical duties or his administrative or non-clinical duties.²⁶)

In assessing public benefit, it is possible that medical researchers using the records may make discoveries which benefit society; however, such a result is much more likely to come from use of *current* records. An *individual member* of society may benefit from learning health information about another person, for instance where he discovers that an ancestor had a genetic disorder and therefore takes steps to discover if he carries the defective gene; the individual would benefit by that knowledge to the extent that there existed some action possible to avoid or ameliorate the effects of the inherited gene. If this *individual* public benefit were justification, *every* record should be kept.

Patient records are seen as having long-term value by at least one historian of social medicine, Dr Bryan Gandevia, although he is not satisfied

with the GDS's selection method.²⁷ In listing the information in hospital records useful to historians, Gordon includes methods of practice and the dates at which various new medical treatments were adopted²⁸ although it is not clear that he means *patient* records as opposed to other hospital records. Sydenham emphasises that "almost any and every type of source is a potential gold mine to an historian of medicine" and considers there is "a great deal to learn by studying the role of the patient as well as that of the practitioner".²⁹ (If patients feature at all in any documentation of health care, the patient record is the most likely place.) Aronsson, in considering another type of case file, points out that "many researchers relish its anecdotal value".³⁰ Assessing the benefit to society of social and medical history is beyond the scope of this paper.

Under the generally accepted grounds on which confidentiality can be breached, the legal requirement is the strongest. Some public benefits can be foreseen and there may be benefits to individuals. On grounds of having patient's consent, there is no justification for transferring records to an archives. However, health records of earlier times (albeit in less detail) are already in the PRO indicating that transfer is an accepted procedure.

It is considered that, because there is a legal requirement, there is justification for breaching confidentiality by placing patient records in a public archives under the safeguards described.

Reduction of Volume

In considering how to reduce the volume of individual patient files, Reed lists three options for a retention policy for medical records: to destroy all material no longer needed for patient care, to convert the material to a format needing less space, or to retain only a portion of the whole.³¹

For a permanent retention, the first option would need to be: to destroy all material not needed for long-term research.

An example of the first option is described by Mitchell *et al.*³² In a scheme implemented in a Scottish hospital in 1967, if a patient did not attend for six years, any discharge summaries³³ were removed from the file and retained, the folder and other contents being "removed to a dead store and destroyed when the store is full".

Space problems for current records in Victorian public hospitals do not justify this as a records management technique but such a process could be used at the time the record becomes eligible for destruction. However, Anderson points out the difficulties with this technique if record content is not standard across agencies.³⁴ (Victorian hospital patient records would be sufficiently standardised for this to work if the solution were otherwise acceptable.) The more parts of the record to be removed for retention, the longer each record would take to process and therefore the greater the cost (labour was cheaper in 1967). This would be a very expensive option.

With no experience of which parts of the records will be used by researchers in the future, it would be difficult to select the particular sheets deserving retention. In Victoria, for example, retaining only discharge summaries would result in incomplete coverage because, if a patient is treated in hospital by his general practitioner, a summary is not usually prepared; however, the coverage would be considerably greater than the present one-in-one-thousand retention. Summaries vary greatly in quality; those prepared by junior medical staff (the majority) are described by Gandevia as "highly unreliable".³⁵

Reed's second option would involve microfilming or other miniaturisation. At least one Victorian public hospital microfilms some parts of all patient records, and some hospitals microfilm all of some patient records; however, it would not be feasible, economically, to microfilm the balance of all public hospital patient records for archival retention.

Cook discusses a different solution: to offer some of the records to other repositories.³⁶ Only places of deposit approved by the PRO could be eligible but, even were the HDV and PRO to approve, places of deposit could be expected to be less than enthusiastic about acquiring quantities of records with such a long closure period.

Reed's third option, retaining a small proportion of the total, has been the one taken in the GDS. Ideally, the method of choosing this small proportion should result in records that could satisfy medical researchers, historians studying both social history and history of (as McKeown puts it³⁷) "the great men and great movements" and also the genealogist. However, Reed quotes the General Medical Superintendent of Sydney Hospital regarding destruction of records: "One of the fears medical officers (and some hospital boards) have is that some day some vital piece of research information will be unearthed from the mass of stored medical records. There is thus a reluctance to destroy any records. In *most* cases this fear is groundless as *most* medical records in *most* hospitals are quite unsuitable for research review."³⁸ (The Medical Superintendent's emphases.) It may therefore be more rewarding to select patient records for their potential value to other potential users. Newman suggests that medical records be kept for historical rather than scientific research.³⁹

A limited literature review made when preparing the GDS revealed no sampling or selection method for patient files that seemed easily implemented. No reference was found to a method in use, as opposed to a description of an idea (the search predated publication of Reed's paper⁴⁰). A sampling method should enable conclusions drawn from the sample to be applied to the population. Selection is purposive sampling.

A necessarily brief summary of possible sampling and selection methods should illustrate the difficulties. Gordon describes the basic problems in a more academically reliable form.⁴¹

A random sample (using the patient record number⁴²) is obviously not an easy matter to implement. At Sydney Hospital, where some random sampling is being used, the computer program was supervised by a person with a doctorate in random sampling.⁴³ Designing a random sample for the State as a whole (rather than for a single institution) is hindered by the variation between hospitals in the number range currently being used: older or busier hospitals are up to very high patient record numbers (six digits long) while others are still at much lower numbers. It was not clear, when preparing the GDS, how random numbers would produce a more representative sample than taking every, say, thousandth record (this is further discussed below). Gandevia also doubts whether "it would ever be possible to produce a genuinely random sample".⁴⁴

Any selection technique that involves a review of record content at the time of deciding between destruction and transfer must be timeconsuming, even if the criteria for selection are clearly defined. Such a review may also need a high degree of skill to reach a decision, at the extreme requiring a doctor's specialised knowledge. Further, the selection criteria may raise ethical problems.

For instance, selecting "notable cases" has been suggested by the British Public Record Office: records which relate to a famous or infamous subject or to a notable event or to a precedent within that specialty.⁴⁵ Although a long period has elapsed by the time the records are available for public inspection, such a selection method draws unsuitable attention to the records at the time of selection and transfer.

Cook notes a method of selecting only those names appearing in "Who's Who".⁴⁶ For Victorian public hospitals, this would result in a very small permanent collection!

Such methods would have no statistical validity, neither would they provide much for the social historian although McKeown's historians of "the great men and the great movements" would be satisfied.⁴⁷ The reactions of the descendants of record subjects could be expected to vary according to whether the subject had been famous or infamous.

Gandevia favours a representative sample made on a selective basis, almost certainly varying in detail from one hospital to another.⁴⁸ To develop the variety of detail necessary for more than 160 hospitals and describe it in a single GDS are tasks not easily faced.

Making a "representative selection" has problems at two stages: deciding

what is to be represented and then finding the cases. It may be decided to illustrate types of cases and types of treatments.⁴⁹ Deciding on a list of "types" that might interest future researchers would not be easy. Any list would have to be defined in terms of usual record content and preferably only include criteria which are routinely indexed.

Making the sample "representative" has its own problems. It would be necessary first to know the size of the "population" of each type. If it were decided, for example, that one "type of case" to be represented is "occupational disease", there is no method currently available to determine how many admission are caused by diseases resulting from a person's work. Even if it were, would all "types of cases" be represented by their proportion to the whole? For instance, if "obstetric" were to be a "type of case", it would be a large proportion yet there would be far less variation in the records of obstetric patients than there would be in those of occupational illnesses.

Assuming the types of cases to be represented and their relative proportions have been decided, the indexes can be consulted but even this is not straight forward. A single record will contain the papers of all admissions and all outpatient notes for that patient. Thus a variety of diseases and treatments are likely to be included (making the record eligible for selection under more than one heading). The patient may have grown many years older during the currency of the record (making stratified sampling or selection by age more complicated). The patient may have changed address or marital status (making stratified sampling or selection by area of residence or marital status more complicated). Mercifully few will have changed sex.

Another volume reduction method considered was to keep, say every tenth year, all records eligible for destruction in that year. This would result in many more records being tranferred. Unless the year chosen was different for different groups of hospitals, the PRO would have uneven work-loads. A variation would be to keep all records *created* in specified years; as these records would become eligible for destruction at different times (fifteen years after *last* attendance of the particular patient), the work load would be spread for the PRO. Neither of these methods would satisfy the statistician.

Another option would be to select "specimen" hospitals and retain *all* records from those institutions and none from the rest. It would be difficult to choose hospitals and give a fair representation of hospital services in Victoria and the result would have no statistical validity for the State.

Appendix 3 of the GDS suggests a method for identifying patient records for permanent retention, chosen for its ease of application: a serial sample where records are retained if the record number ends in "999" (that is, every thousandth record created). In the filing method of most Victorian hospitals, such records are grouped together in the same shelf area using a filing system called "reverse terminal digit".⁵⁰ The procedure, therefore, is to cull eligible records from that file area and process them for transfer. Other file areas are then culled but the records destroyed. The selection method suits the filing method.

A hospital wishing to use any other method may do so after consultation with the PRO.

Because issuing the GDS could not be delayed, the simplest method was included in the absence of any other that could be discovered or thought up, expecially bearing in mind the method had to be capable of implementation in *every* public hospital in the State. The alternative would have been to omit a permanent class resulting, eventually, in the complete destruction of contemporary hospital patient files. Even had some hospitals taken the initiative in retaining some of their own records permanently, this would not necessarily have made them as accessible as they eventually will be in the PRO. Another possibility would have been for each hospital to devise its own method of selection for transfer and have that incorporated into the GDS: an administrative nightmare for the PRO and confusing for staff moving between hospitals.

It should be borne in mind that, as record numbers are allocated to patients in order of their first attendance at the hospital, selecting every one-thousandth should represent the whole as much as this seems possible. If more females than males are patients, more records of female patients will be retained; if there are more patients who first attend with asthma than with angina, more records for asthma patients will be retained; if more people are registered as new patients in a particular year, more records of that year will be retained; if more patients attend a first particular clinical speciality, more records of that speciality will be retained.

For researchers needing statistically valid data there will be published summary statistics. There is also the computer collection of data from all Victorian public hospitals (now being extended to private hospitals) which includes, for all inpatients, some socio-demographic information (no identification but age, sex, country of birth, Local Government Area of residence, etc), information about the admission (public/private patient, length of stay, etc) and diagnosis and procedure codes. If archival survival of this collection can be achieved, it may have more value to scientific researchers than any sample of records although it will not satisfy the historian needing narrative.

It was felt that the chosen method for reducing the volume of patient records was the only practical one at the time. Should a more satisfactory selection/sampling method be developed in future, or be discovered in use elsewhere, the GDS can be amended. Although we were not aware of the report of the King's Fund Centre symposium on hospital clinical records⁵¹ when preparing the GDS, it was a relief to see that no clear solution had been found. Roper made the point that "retention of every nth file by every authority, nationwide" would be more practicable than random sampling nationwide and that "adoption of a selection programme [as opposed to a sampling programme] carries a high risk that the selection may prove ineffective in later years".⁵²

Some other Appraisal Considerations

Economic factors have to be taken into account. It is difficult to estimate the number of patient records that will result each year from the onein-one-thousand example: although there are over half a million *admissions* to Victorian public hospitals each year, a proportion (unknown to HDV) are *re-admissions*. The one-in-one-thousand applies to *records*, not admissions.

The expenses incurred in having records in an archives are only defensible if access is available, even if restricted or delayed by a closure period. During the closure period, access will be permitted to researchers under circumstances similar to those established for the psychiatric records recently accessioned by the PRO: an ethics committee (of the original record owner) assesses each research project and researcher, and specifies conditions under which work can be done.

It is now part of archival ethics that no distinction be made between researchers.⁵³ However, all types of medical research are subject to assessment for funds and permission of various kinds; an appropriately constituted ethics committee deciding on access to patient records in the PRO would merely be one more step for a medical researcher and is unlikely to be seen as discriminatory. Further, these decisions are not being made by archivists but by the original owners.

During the closure period, any request for *individual* records (that is, named records) will be referred by the PRO back to the original hospital for decision and processing, whoever made the request (researcher, patient or other person).

Potential users of the records after the closure period, apart from historians, would include biographers and genealogists. Some of the records' qualities will cause problems for archives staff. To search by disease or treatment requires a knowledge of medical terminology and the coding system(s) in use at the time the record was indexed by the hospital, assuming the coding books are still available so long afterwards (the coding system used in Australia is revised every ten or fifteen years⁵⁴).

Archivists will be asked, at least by non-medical users, for assistance in reading handwriting (it has been said that doctors receive special training in illegibility) and in interpreting the abbreviations and medical terminology used in patient records. Patient records can be appraised by the two classical criteria of evidential and informational value. They are perhaps the only evidence of hospital activity in relation to *patients*. In future, to know from administration files how hospitals were financed, staffed, managed, etc, without knowing how patients were treated has "Yes Minister" overtones.⁵⁵ Craig states that, although most work has used administrative records, the records of hospital medical practice can provide the richest material for the historian.⁵⁶

Hospital patient records are an example of records as a communication system, being used by various disciplines of health care providers on each shift through the entire week and over time (for later admissions).

While the informational density of these records is low, they are about people and about methods and performance. For instance, while text books describe how operations *should* be performed, patient records describe how they *are* performed.

It will be many years before an assessment can be made of the appropriateness or otherwise of placing modern hospital patient records in the PRO.

Conclusion

Placing hospital patient records in a public archives is permissible, in Victoria, when assessed against current requirements for the confidentiality of records. Choosing a method of reducing the volume of patient records is no easy matter and the main value of the serial sample suggested in the GDS is its ease of application. These records will raise some problems for archivists of the future. Whether the effort will be worth the eventual use, it is too soon to assess.

FOOTNOTES

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- 2. Health Commission of Victoria and Public Record Office Victoria. General Disposal Schedule for patient information in public hospitals, November 1980.
- 3. (Victorian) Drugs, Poisons and Controlled Substances Regulations 1985.
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- 24. (Victorian) Public Records Act 1973, s2(1).
- 25. *ibid*, s12.
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- 53. Cooke, Anne. "A code of ethics for archivists: some points for discussion" Archives and Manuscripts, Voll. 15, No. 2, November 1987, p. 102.
- 54. Victoria has used the current revision of the International Classification of Diseases, World Health Organization, Geneva (or a system based on ICD).
- 55. Lynn, Jonathan and JJay, Antony. "The compassionate society" in Yes Minister, London, British Broadcastings Corporation, 1982, pp. 11-40. In this television comedy programme, staff of a hospital is seen to be too busy running the hospital to admit any patients.
- Craig, Barabra Laze, nby. "The Canadian hospital in history and archives" Archivaria Vol. 21, Winter 1985-86, p. 63.