

## ***Cutting the Gordian Knot: Or How to Preserve Non-Current Clinical Records Without Being Buried in Paper***

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### ***Résumé***

La masse des dossiers cliniques des hôpitaux générés durant les cinquante dernières années est largement perçue comme un problème, tant au niveau de l'espace requis pour leur entreposage que des coûts afférents à leur conversion sur des supports moins volumineux. Les auteurs du présent article soutiennent que le problème réel n'en est pas un de volume mais plutôt d'inutilisation; laquelle résulte d'un classement inadéquat ainsi que d'une information contextuelle lacunaire. Présentement, l'accès aux dossiers cliniques non actifs est ardu et se fait plutôt à l'aveuglette. Ainsi le nombre réel d'utilisateurs de ces dossiers est peu élevé malgré la grande valeur potentielle de ces informations, spécialement pour les épidémiologistes et les cliniciens. Durant le cours de la recherche menée au *British National Health Service* un éventail de solutions possibles aux problèmes, aussi bien présumés que réels, a été examiné. Les recommandations, bien que conçues pour le *National Health Service* d'Écosse, peuvent aussi s'avérer pertinentes dans d'autres milieux. Le plan défendu ici a pour but de créer une «tangente» visant à envisager les dossiers cliniques comme une ressource utilisable et valable plutôt qu'uniquement comme une source d'embarras. Quelques unes des questions et alternatives soulevées ici à propos des dossiers cliniques sont également pertinentes pour l'évaluation de d'autres séries du *PIPs (Particular Instance Papers)*; elles ont également des incidences sur la collecte et la conservation des données informatisées.

### ***Abstract***

The quantity of hospital clinical records generated in the last fifty years is widely perceived as a problem, not least because of the storage accommodation required to house hard copy records and the costs involved in converting them to less bulky media. The authors of this paper argue that the real problem is not bulk but

lack of use. This in turn is the consequence of inadequate indexing and contextual information structures. At present, access to non-current clinical records is difficult and inherently haphazard. As a result, the constituency of actual users is small. Yet potentially valuable data, particularly for epidemiologists and clinical researchers, is contained within these records. In the course of research conducted in the British National Health Service (NHS) a variety of possible solutions to both the perceived and real problems have been examined. The recommendations made, although addressed primarily to the circumstances of the NHS in Scotland, may be relevant elsewhere. The scheme advocated here is intended to create a "virtuous circle" of use leading to a willingness to regard clinical records as a resource to be utilized and valued rather than as a problem. Some of the issues and alternatives considered in respect of clinical records are relevant to the appraisal of other series of PIPs (Particular Instance Papers); they also have implications for the collection and storage of data in electronic form.

When the Scottish novelist Eric Linklater visited the United States in the late 1920s he was impressed by American medical record-keeping. Accordingly, when one of his characters, Juan Motley, enrolled at a fictional New York State university he was subjected to a thorough medical examination.

Nor were the examiners content with examining. They also chronicled. Juan's height ... and his weight ... They wrote this upon a card. He had had chicken-pox ... measles ... his tonsils removed ... a boil evacuated ... all this was solemnly recorded. [Juan] ... thought with awe that he now had a place in the archives of America ... secure, immortally card-indexed, pigeon-holed in some desk as vast as eternity. ... Now at last had the People a place and a name on the scroll of their country. Now at last were their qualities and characteristics ... classified and recorded with those of generals and statesmen and builders of cathedrals. The future was being made safe for biography. ... Perhaps some inhuman colossal Mendel was preparing the data for future generations of scientists ....<sup>1</sup>

On both sides of the Atlantic the amount of medical information collected, and the way that that information was stored, changed dramatically in the first half of the twentieth century. Although not the only impetus for change, an important factor in this information revolution was the belief that the collection of ever greater quantities of medical data was a desirable objective. This contrasts with current assumptions, certainly within the National Health Service in Scotland. The first section of this paper will provide a brief overview of the changing nature of hospital clinical record-keeping in Scotland since the end of the last century. Section two will examine some of the problems associated with non-current clinical records which have arisen since the 1950s. The third section provides a review of commonly advocated "solutions" to these problems. The paper will conclude with an overview of a range of sampling and enhanced indexing techniques which have implications for the future retention or destruction of non-current hospital clinical records and other series of Particular Instance Papers (PIPs).

### *History of Medical Record-Keeping, Particularly in Scotland*

The development of the clinical record since 1890 has reflected the increasing complexity of the social, administrative, and medical functions of health care delivery systems. In order to understand the difficulties associated with medical record administration in the 1990s, it is necessary to provide a brief overview of these developments and the consequences they have had for the long term retention of medical records for research purposes.

In the 1890s, hospitals' clinical information was recorded in ward journals. These documents differed from patient case files in a number of important respects. Most salient amongst these was that each record was composed of many episodes relating to many different patients. The connecting factor between these episodes was that all had presented to the same administrative subdivision of the hospital. In this respect the ward journal betrayed its ancestral roots. These lay in clinicians' personal notes, their *aide mémoire* based on their experiences.<sup>2</sup> Until the 1930s it was still common for ward journals to be identified by the name of the consultant who had treated those patients. As suggested by their title, the records were often housed in the ward or at least within close proximity to the staff responsible for their creation and maintenance. This encouraged a sense of local responsibility for particular groups of records, but led to a highly devolved system of record-keeping within the institution as a whole. Another pointer to the origins of the system is provided by the method of internal filing. The practice of entering notes into pre-bound volumes was geared towards chronological record-keeping. This encouraged the assembly of records which provided a good view of the mechanics of day-to-day health care provision--a form of institutional diary--but impeded the collation of material pertaining to any single patient to form a case history.

The other major component of hospital record systems in the 1890s was the admission register. This was primarily an administrative tool. In most hospitals it also served as the only overall index to the ward journals, albeit one which was extremely laborious to use. The administrative uses of the admission register included: compilation of admission statistics; calculation of cure and mortality rates; compilation of patient-stay statistics; and checking the abuse of recommendation privileges by subscribers. There was a tendency for admission registers to become more comprehensive over time. By the late nineteenth century information about age, marital status, religion, and country of birth was collected routinely and provision was made for additional information to be added in a remarks column.<sup>3</sup>

From the turn of the century onwards this system became increasingly outmoded. There were three principal reasons for this. First, the introduction of new technologies placed strains on the traditional form of record-keeping. Pre-bound volumes were not compatible with duplicators and typewriters. In order to take advantage of the new technology, typed or duplicated documents had to be inserted into the record, often by pasting sheets of paper to the edge of the page.<sup>4</sup> As a result, ward journals became cluttered and difficult to interpret. The trend was exacerbated by the introduction of laboratory technologies.<sup>5</sup> At first the results of tests were transcribed by hand along with daily observations. As the volume of technical data increased it became impractical to transcribe results of tests. Instead, laboratory reports and ECGs were pasted directly into the record alongside other typed and duplicated material.<sup>6</sup>

Important material was lost as appended documents became unstuck, and ward journals became untidy and difficult to use. Worse still, bindings stretched beyond their limits burst--the ward journal system of record collection literally came apart at the seams.<sup>7</sup>

Secondly, the record-keeping functions of hospitals became increasingly specialized as clinicians were relieved of routine clerical tasks. Many semi-skilled staff were hired, especially stenographers, telephone operators, and typists. Larger areas were laid aside for record administration. The new medical records offices were usually centrally-located and under the charge of a specialist medical records officer. Responsibility for the overall upkeep and maintenance of the record was transferred from medical to clerical staff. A particularly important aspect of this transformation was the manner in which a new record-keeping culture began to dictate the form and pace of intra-hospital relationships. It defined groups within the hospital in terms of the paperwork they were responsible for. In a highly interrelated system, it also monitored the output of various groups, so that the source of obstructions in the normal flow of documentation could be readily-traced.<sup>8</sup> These transformations are important, as they helped to redefine the medical record as a tool of hospital management. The days of "Dr. Finlay's case book" were numbered.<sup>9</sup>

Thirdly, developments in the way that medicine was taught placed increasing emphasis on the value of complete case histories. It was felt that while it was desirable to present students with patient-based examples, these were not readily accessible under the ward journal system. As a result, the latter was perceived as an obstacle to teaching. Another impetus for change was provided by clinicians anxious to evaluate the results of new techniques or who worked in fields where the value of long term follow-up had already been demonstrated, for example, orthopaedics, tuberculosis, and cancer.<sup>10</sup> This created a demand to keep more information and organize that information in a more appropriate manner.

The evolution of the unit patient file or case file was a direct response to these pressures. The first general hospital known to have used case files (in New York) inaugurated the system in 1916. An earlier use is known in Britain: the Three Counties Asylum in Bedfordshire adopted a system of individual patient files in 1912.<sup>11</sup> It was in these years, immediately before the World War I, that robust manila files (known as "Lloyd George Envelopes") were introduced for General Practitioners' (GPs) patients insured under the British National Health Insurance Acts. Most GPs seem to have found patient files much superior to the old casebooks; the latter rapidly went out of use in most practices.

In Glasgow the Royal and Victoria infirmaries made some use of patient files in the inter-war years. These, however, were flimsy things--just large sheets of paper folded to make folders.<sup>12</sup> Some of the advantages which should have followed from a thorough-going adoption of patient case files were not achieved. Each year's files were bound up as volumes in order to protect the flimsy paper. As they were bound together according to which ward the patient had been treated in, complete case histories were not assembled.<sup>13</sup>

Following the creation of the National Health Service (NHS) in Britain in 1948, the use of the unit case file system (in which a patient name index was an indispensable necessity) became virtually universal. The unit file system of medical record-keep-

ing was designed to increase the efficiency with which case histories could be located, enable physicians to give better continuous care to patients, and furnish information which upon subsequent analysis could lead to improvements in the quality of health care provision. The basic principle of the unit file was that instead of medical records being ward, consultant, or practitioner based, the identifying unit would become the patient. Each patient's file was to contain all records pertaining to that individual from ante-natal care to post-mortem examination. The system demanded that a unique number be allocated to each record and that when a patient re-attended hospital the existing file be located and all newly generated records inserted therein.

NHS administrative bodies in Scotland actively encouraged standardization in the use of unit case file systems. For instance, a 1959 report promoted the use of standardized forms.<sup>14</sup> The report also recommended that each Regional Hospital Board should have a senior officer with overall responsibility for medical record matters. Unfortunately, the latter recommendation was widely disregarded.

By the early 1950s the medical record had developed into an extremely complex document. While its principal purpose was to facilitate the immediate treatment of the patient, it had a variety of subsidiary functions. Unfortunately, not all of these were compatible with the primary aim of immediate patient management. The most important of these subsidiary uses were: to aid the continuing care of the patient; to be of collective use as a store of important epidemiological information of potential benefit to the community; to form a depository for important legal documentation; and to provide a source of administrative data. Contemporaries identified three problems with the unit case file system which urgently required to be addressed. Firstly, there were considerable problems in gathering NHS management information, and even greater problems in manipulating and using the data which was available. Secondly, it was possible for one patient to have more than one file in a single hospital. Thirdly, there were great difficulties in establishing record linkage between hospitals. The last two difficulties arose largely because of the chronic failure of both staff and patients to use the patients' NHS numbers. These would have provided unique identifiers had they been universally utilized.<sup>15</sup>

Accordingly, in 1961 an additional patient data system was introduced to overcome the deficiencies inherent in the multiplicity of existing hospital-based unit case file systems. The new system was SHIPS (the Scottish Hospital In Patients Statistics system) perhaps better known as SMR, from its principal input document, the Scottish Morbidity Record form number one (SMR1). In essence, SHIPS was to be a central database containing summary data on all in-patient episodes in NHS hospitals in Scotland. SHIPS aimed to provide a better quality of NHS management information and to do so in a way which would enable the data to be handled and used more flexibly than had previously been possible. In addition, SHIPS aimed to provide the basis for enhanced epidemiological and public health research. After five years of operation, the SHIPS system was reviewed and modified. The changes made to the SMR1 were designed to make the form function as a discharge summary, in the expectation that this would promote the integration of the SHIPS system with the hospitals' own clinical records systems.<sup>16</sup>

### *The Present Situation: Problems With Non-Current Paper and Card Records*

Whilst present-day epidemiologists might not be wholly charmed to be described as "inhuman colossal Mendels," Linklater was percipient in foreseeing the value of medical archives for scientific enquiry. Unfortunately, he was mistaken in imagining that the creation of large data sets was, in itself, sufficient to underpin such research. It has long been apparent that while vast amounts of data have been assembled, it is difficult to retrieve, order, and manipulate that information for either clinical or administrative purposes.

Two phenomena are particular causes of concern: the rapid growth of record series and difficulties in accessing data for reasons other than immediate patient care.

Since the adoption of unit case files the amount of space occupied by medical records has expanded at an alarming rate. To provide an example of the scale of the problem, the Glasgow Western Infirmary's ward journals, currently housed in the Health Board Archive, occupy 130 linear metres.<sup>17</sup> The Western Infirmary currently generates about 200 linear metres of unit files in a single year. That is thirty-six per cent more material than the hospital accumulated in its first sixty-six years of existence. Overall, the hospitals in the Greater Glasgow area create about one linear kilometre of new paper and card each year. Writing in the late 1960s, J.H. Mitchell described the growth of medical records departments as a "malignant neoplasm" at the heart of the hospital.<sup>18</sup> This situation has arisen for three reasons. The National Health Service treats a greater proportion of the population than was the case with pre-nationalized health care. Much more space is occupied by record covers in a unit file system compared to a ward journal system. Unit files are designed to allow more information to be retained, indeed they encourage the retention of information. This would not necessarily be bad if the information had some value. Under the current system of information management, however, the value of non-current clinical files is remarkably low.

For a record to have value there must be some means of delivering the data it contains to end users. Hospitals do of course have facilities which do exactly this. Scottish hospital indexes rarely, however, contain details other than the name, address, date of birth, and sex of the patient.<sup>19</sup> This is adequate for the purpose of immediate patient management, but is not particularly suited to the needs of other potential users, particularly epidemiologists. The main effect of this is a marked decrease in the value of clinical records over time.

The shelf life of a record varies according to intended use. Information considered essential to the immediate management of the patient may have a lifetime which can be measured in weeks or even days. Other data of use in providing continuing care will have varying lifetimes, but these rarely exceed the lifetime of the actual patient. In the case of legal requirements, there is usually little argument for keeping a record after sufficient time has lapsed for legal action to be brought. For some administrative and legal functions (for example, long term audit) it may be deemed prudent to keep a sample for thirty or forty years. It is, however, only secondary analysts like epidemiologists and medical historians who argue that records should be kept for much longer periods than this. The critical point here is that users whose areas of interest depend upon lengthy retention periods are ill-served by current indexing facilities. Without a flexible diagnostic index the huge store of information con-

tained in non-current clinical records is placed beyond the reach of most potential users. As a result, few clinical records are ever consulted after the patient has ceased to present at a hospital.

In many ways the unit file system has defeated the purposes for which it was created. Rather than making health care records more accessible, vital information has been lost in files which are untidy, in a poor state of repair, and inadequately indexed, and which contain much that is either out of context or of no immediate importance to the majority of users.<sup>20</sup> The essential problem is that the unit file system is incapable of performing several diverse functions at once. The net result of these failures is that non-current clinical records are perceived as possessing little value. To date, tens of thousands of post-1948 records have been destroyed. This is a trend which is likely to continue.

### *Problems with Electronic Summary Data*

Whilst much concern has been expressed over the rate of destruction of non-current clinical records, the existence of an alternative source of information, in electronic summary form, has muted these expressions of concern. Despite their advantages, however, there are clear indications that the electronic summary data contained in the SHIPS database are, in many respects, a poor substitute for the full clinical record. Since the early 1970s several studies have highlighted serious deficiencies in the accuracy of SHIPS diagnostic coding, particularly with the SMR1 and 4 programmes.<sup>21</sup> This is not a local phenomenon.

Diagnostic classification schemes have encountered difficulties ever since prototypes were drawn up in the 1840s. At the heart of these problems lies a tension between what administrative statisticians on the one hand, and epidemiologists on the other, want from summary data. The statisticians argue for broad categories of data to facilitate the development of public policy, while the epidemiologists require more detailed information.<sup>22</sup> To illustrate this by way of an extreme example, imagine a two-fold classification—alive or dead. This will produce a high uniformity of response since the procedures for filling out a coding form are routine; each subject is either reported as alive, dead, or neither (no available information). This will produce highly accurate data of virtually no epidemiological use.

In order to obtain more detailed data, clinicians must be asked not if their patient is alive or dead, but what disorder, if any, they are suffering from. In this case the question is not routine but open ended. That is, it no longer invites three responses, but a large variety. Classifying this data requires that judgements are made as to which of many categories individual responses are placed in. The larger the choice of categories the greater the probability that two individuals will classify the same situation in two different ways.<sup>23</sup>

The International Classification of Diseases (ICD), the classification system that SHIPS and many other systems are based upon, is a compromise between both approaches. The resultant limitations are apparent in all ICD-based data systems. In the case of SHIPS, these limitations are compounded by a lack of contextual information (laboratory reports, nursing notes, referral letters, etc.).

Because of these inadequacies it is dangerous to view electronic summary data as an adequate replacement for paper and card clinical records. Indeed, it is evident that reference to clinical files can play an important part in interpreting, checking, and validating summary returns. Rather than summary data providing cover for the destruction of hard-copy records, the loss of the latter may critically impair the utility of the former. To paraphrase Oscar Wilde, to lose one source of data may be regarded as a misfortune, but to lose both would look like carelessness.

### *Implications of Clinical Record Destruction*

Other than as a means of checking SHIPS data, will it matter if non-current clinical records continue to be destroyed in large numbers? The answer to the question is almost certainly yes. Clinical files are an irreplaceable resource. Haphazard data destruction will have an effect on the quality (and in some cases viability) of future epidemiological research in areas such as:

- follow-up studies
- cohort studies
- long-term evaluation of medical intervention
- mapping changes in disease environments
- monitoring presenting populations
- evaluating diagnostic trends.<sup>24</sup>

### *Is There a Solution?*

In searching for a solution to these problems it is important first to rule out some false hopes. The record storage issue has two facets, issues of bulk and issues of access; any initiative aimed at addressing storage problems must tackle both. Thus, retention programmes which attempt to persuade health administrators that all clinical records should be preserved without an accompanying improvement in access arrangements are likely to fail. This includes schemes which attempt to transfer existing records to a different storage medium, such as microfilm, microfiche, or optical disc.<sup>25</sup> The other bulk reducing option, file weeding, produces only modest savings in space and is extremely costly in staff time.

It is also unrealistic to expect public record offices to accept non-current clinical record series. A large number of badly indexed files which are closed for public access for seventy-five years and have been physically removed from the location where the relevant ethics committee has jurisdiction are not an enticing prospect.<sup>26</sup>

A realistic solution to the problem has to be built around four principles:

- any retention programme should seek to combine the varying strengths of original clinical records and electronic summary data to create a flexible information management package;<sup>27</sup>
- sampling offers advantages over other bulk reducing options. This is because sampling can provide the opportunity to reclaim substantial record storage space



at a relatively low cost, while protecting the interests of many potential users of clinical data,<sup>28</sup>

- adequate information must be provided for future users so that they can locate records germane to their areas of interest and employ that information in an effective manner;
- if possible, records earmarked for long term retention should not be removed from the jurisdiction of the administrative bodies responsible for their creation.<sup>29</sup>

### *Where is Sampling Applicable?*

Sampling does not offer a panacea to the problems of record retention and it is worth stressing that whatever sampling technique is applied, some aspects of the original record population will be lost. While some potential users will be disappointed by a sampling programme, the same could be said of any other sustainable preservation programme. In many ways the justification for archival sampling is simply that it can provide a sound procedural basis to the thorny question of what should be kept and what discarded.

In considering the techniques described below one point should be borne in mind. Each design should be carefully considered in relation to the data to which it is to be applied. Some designs, for example, are particularly suited to collections of records filed in certain ways. A sampling system which is difficult to apply to a record series may be counter-productive in that implementation may prove expensive and/or time-consuming. Further, if many errors are committed in the process of drawing the sample, the utility of the exercise will be undermined.<sup>30</sup>

In general, sampling procedures may be appropriately applied to large groups of records assembled using standard practices and procedures. Many clinical record series and other PIPs fall into this category. Small collections of hospital records displaying much variation in content, however, should not be sampled.

### *Alternative Sampling Strategies*

With random sampling, a record is selected from a sampling frame<sup>31</sup> in a way that ensures that there is an equal probability of any other record in that series being selected in its place. This procedure is repeated until a sample of the desired size has been assembled. This is achieved by resorting to a random number table or a computer package which generates random numbers. The advantage of random sampling is its relative freedom from sampling bias. It is particularly powerful if only a small sample of records is required. The disadvantage is that if the number of records to be sampled is large the process of record selection becomes laborious and prone to error. For large series of clinical records the technique is likely to prove counter-productive.<sup>32</sup>

Systematic sampling is a technique commonly resorted to in order to overcome the disadvantages associated with random sampling. The process involves drawing records from a sampling frame at particular intervals. The usual procedure is to take every *n*th record after a randomly chosen start. The advantage of the technique is

that it is relatively simple to execute. This can lead to substantial time savings and reductions in the number of mistakes made during the selection process. Systematic sampling can work particularly well in hospitals which employ terminal digit filing.<sup>33</sup>

The main disadvantage is that systematic sampling is prone to underlying patterns embedded in the data. This is perhaps best illustrated through the use of an example. Imagine a clinic which sees one set of patients in the morning and a completely different set in the afternoon. If approximately the same number of cases presented in the morning and in the afternoon and the amount of patients seen over time remained constant, a systematic sample of the records might consist of cases drawn entirely from one set of patients. A further disadvantage is that the technique provides no information on the relationship between sequential observations. Thus, a systematic sample of accident and emergency admissions might lead one to conclude that traffic accidents never cause injuries to more than one individual.<sup>34</sup>

Cluster sampling involves dividing the frame into sections, for example, the years that patients were first treated or the post-code areas in which they are resident. It is these clusters or chunks of data which are then sampled. There are several advantages to this procedure. Splitting the frame up into convenient clusters may increase the speed and efficiency with which a sample can be drawn. A common example of this is a sample drawn according to the first letter of the surname from an alphabetically-filed archive. Another advantage is that the procedure can be used to facilitate record linkage. An example of this would be a record population which was grouped according to year of creation and then sampled by taking every tenth year to coincide with the census.<sup>35</sup> The obvious use of cluster sampling in relation to clinical files is to divide the record population up according to creating institutions. This much-abbreviated frame can then sample by hospital. All these procedures, however, are prone to one particular form of bias. This arises when one or more of the clusters of data to be sampled are distinctive in a manner important to subsequent analysis. The most common example of this is that arising from alphabetical sampling based on the first letter of patients' surnames. In Britain, for example, a dilemma here is that if M is included the sample will be biased towards Gaelic (Mac and Mc)-derived names and if it is not the reverse will hold.

The problem with sampling particular institutions is that it is extremely difficult to envisage a single hospital which is representative of all aspects of health care in its particular region. The dilemma here is that because the records selected for preservation will be an unrepresentative fragment of the original record population they become difficult if not impossible to interpret in a wider context.<sup>36</sup> We are inclined to think that this approach is symptomatic of a desire to retain the records of high status hospitals at the expense of providing a representative picture of health care. An advantage of the approach is that retention of hospital patient records may encourage the retention of important supporting documentation, particularly administrative records. This would, no doubt, be a great help to those engaged in writing institutional histories. This advantage, however, must be weighed against the limited epidemiological value of institutionally-based record selections. A theoretically attractive development of this approach would be a scheme in which all the clinical records of one institution are preserved whilst those of surrounding hospitals

are sampled. This would provide epidemiologists with sufficient information on the attributes of the original record population to place the records of the chosen institution in a meaningful context. Such an undertaking, however, would be both complex and expensive.

Stratified sampling is a technique where the frame is split into strata. These strata are then sampled more or less intensely according to their representation in the original record population and the aims of the study. For example, if it was decided that the frame should consist of all diagnoses recorded in a clinical record series, a stratified sample might consist of one per cent of commonly-encountered disorders, ten per cent of uncommonly-encountered disorders, and one hundred per cent of all rare disorders. Once the design of the frame and sampling proportions have been agreed upon, records can be drawn from each stratum by either systematic or random sampling as described above.

The advantage of stratified sampling is that it can reduce the size of the sample drawn without compromising its integrity. This is especially true for record series which contain a large number of similar records occasionally interspersed with more unusual observations. If, for example, a five per cent sample was drawn from such a record series without the use of stratification it is likely that many unusual observations may be poorly represented or fail to be sampled at all. A stratified approach would reduce the overall size of the sample by drawing fewer records containing routine observations, but might also ensure that less common aspects of the record population were preserved in meaningful quantities.

There are, however, several considerable disadvantages with stratified sampling. First, it is imperative that a great deal of information is known about a record series before a stratified sample can be drawn. For example, if it was decided that stratification would provide the best means of preserving diagnostic information, the sampling frame could not be constructed unless the proportion of diagnoses contained in the original record population was known and there was some way of identifying which files contained information on which disorders. It is also important that this information is preserved along with the sample. Future researchers must be told the proportion of the original record population contained in each stratum so that the individual constituent parts of the sample can be re-weighted for use in conjunction with each other. Care should also be exercised that records belonging to one stratum do not become confused with others. If these guidelines are not adhered to, the validity of the sample will be critically impaired and a great deal of effort will have been expended to little avail.

A second disadvantage is that in designing a stratified sample, decisions must be made as to which categories of information are important enough to merit protection. The example offered above was based on the diagnoses recorded in a series of patient files. While some subsequent research programmes might benefit from this approach, others, more interested in, say, the areas of residence of presenting patients, may be poorly served. It is also possible that the range of diagnoses recorded in a clinical record series may be too great to offer adequate protection for each and every different observation. The best justification for a stratified approach may be that it is best to ensure that a limited range of research interests are well served rather than provide a resource which is universally inadequate.

A common problem associated with random and systematic sampling is that they are not very good at preserving unusual aspects of the original data. One way of increasing the utility of a sampling strategy is to draw smaller subsidiary samples to cover a class or classes of records identified as likely to be of particular interest.<sup>37</sup> As with stratified sampling it is essential that subsidiary samples are clearly identified as such and stored separately from a representative sample.

The main advantage of this approach is that it can be much easier to implement than a stratified sample. For example, a systematic sample of every record with a file number ending in fifteen could be combined with several cluster samples composed of all records raised in a census year. In this case, the attributes of a time series (systematic) sample are combined with the advantages of retaining a total count of records raised at regular intervals. There are two principal disadvantages. First, as with stratified sampling, deciding which categories of information are of particular interest and worthy of further protection is an inherently subjective exercise. There is no easy way around this dilemma unless the subsidiary sampling schemes are extremely comprehensive. Second, identifying subsidiary categories is often time-consuming, especially when the necessary identifying data is not included on the file cover.

### ***Summary of a Report Submitted to the Greater Glasgow Health Board by the Clinical Records Preservation Project***

Our report argues that a preservation programme should combine the attributes of two information resources to address the dual problem of access and bulk. First, the electronic summary data can be used to index clinical records.<sup>38</sup> The clinical records can be used in turn to provide rich detail to flesh out the electronic data. It is evident that the research utility of both resources is enhanced when they are held in conjunction. Second, we argue that sampling should be used to tackle the problem of bulk. The electronic summary data can be used to draw representative samples of clinical records for long-term preservation. Sampling initiatives can be used to reduce storage costs while protecting the interests of future researchers.<sup>39</sup>

A summary of these recommendations is provided as follows:

- A five per cent systematic sample of all post-1948 clinical records should be drawn. Systematic sampling was deliberately chosen to increase the speed and accuracy with which a sample could be drawn.
- Electronic summary data should be used to draw a series of stratified samples aimed at preserving files containing infrequently occurring diagnostic data.

These samples should be stored in a Health Board administered archive and an index created utilizing the electronic summary data. Facilities for on-site access should also be provided for the complete run of electronic summary data for all in-patient discharges in the Greater Glasgow area. Finally, information about information should also be made available, so that potential users would know what was in the archive, how it had been assembled, and how they could apply for access.<sup>40</sup>

### *A Tentative Look Into the Future*

Over the past four decades developments in information technology have had an increasing impact on the manner in which the data contained in PIPs is collected, stored, and manipulated. This is a trend which is likely to continue. While we will refrain from hazarding rash predictions as to the nature of these developments, it may be prudent to issue a few words of caution based on current trends.

Electronic medical records currently exist which contain: relational patient administration systems; spreadsheets to facilitate the analysis of laboratory reports; floating windows capable of playing quick time movies; elaborate security mechanisms; and embedded sound files, to name but a few recent developments.<sup>41</sup> These records can be stored by the thousands on WORM (Write Once Read Many times) optical discs in systems which allow many people to access one record at the same time from locations many miles apart. Astonishing as these advances may appear, in some respects they bear parallels to past developments. Just as unit files encouraged hospital administrators, clinicians, and other health professionals to collect more information, the same can be said of electronic systems. In both situations two factors are responsible for the trend towards ever more data: the belief that more is better, and faith in the new system's ability to digest this information and deliver a net return in the form of better administration, improvements in health care, and developments in epidemiological research. As should be clear, however, from the unit case file experience, more data is no guarantee of greater digestive power.

There is a danger here of being blinded by the speed of the available technology. Computers, given the right set of instructions, are very good at locating information. There is nothing new in this; terminal digit filing and card index carousels also resulted in improvements in the time it took to access records. The glitch is that access speeds are irrelevant if the search cannot be targeted at particular pieces of information or groups of files. Without this facility all searches, independent of operating system, will grind to a snail's pace.

Let us elucidate our argument through means of an example. One of the benefits of electronic information storage systems is the potential for "free text" retrieval. Thus if GP referral letters are stored electronically it is theoretically possible to access any letter containing particular words or phrases, for example, "blood pressure." The resultant haul, however, will contain many letters which include variants of the phrase "this patient's blood pressure is normal." In an attempt to overcome this problem we could make the search more specific, for example, "retrieve any referral letter where 'high' occurs within six words of "blood pressure." Narrower search criteria, however, run the risk of excluding some referral letters, such as "this patients blood pressure gives cause for concern," without being specific enough to target others, such as "this patient has hypertension." The situation will become altogether more complex if the files required by the researcher are those for patients diagnosed as having high blood pressure in relation to another disorder. With a large number of referral letters it is unlikely that any retrieval, no matter how many "and/or" qualifiers are added, would be comprehensive enough to square the specifics of a research request with the multiplicity of terminological constructions employed by GPs.

GPs, and other contributors to hospital patient records, could be encouraged to use specific terminological constructions. This is the logic behind medical classification systems such as the International Classification of Diseases (ICD) and the Diagnostic and Statistical Manual (DSM). The use of such classifications is fraught with many problems, some of which are discussed above. In the context of the present discussion, however, the essential point is that arguments over the nature and purpose of medical classification predate the introduction of computer-based technologies by at least a hundred years.<sup>42</sup> These arguments are unlikely to be solved by developments in artificial intelligence as they are not a function of the limitations of the available technology but of the tensions resulting from the differing practices and demands of a range of health professionals.

If there is a lesson to be learned from the past it is that technological advances alone are unlikely to provide meta solutions to the complex problems of medical record storage. Indeed there is a distinct possibility that the introduction of electronic records could exacerbate existing issues.<sup>43</sup> We would argue that the solutions to current medical record storage problems outlined in this article are a first step to avoiding the repetition of past mistakes. We recognize that our arguments are by no means radical. The simple diagnostic indexing systems outlined here will be of limited benefit to many potential researchers. Nevertheless, they represent a substantial improvement to existing arrangements. The aim of such modest improvements in the management of hospital case records is to provide a justification for long-term storage. Initiatives which facilitate research access should help to create a "virtuous circle" where the use of information leads to the application of research findings, which in turn provide the necessary impetus to generate further investment in data collection and information management. In the absence of such developments, it is unlikely that necessary provisions will be made to deposit and maintain electronically-generated PIPs and their associated hardware, software, and data documentation. We repeat that if information cannot be accessed it is unlikely that the investment necessary to guarantee its upkeep will be forthcoming.<sup>44</sup>

### Notes

- \* We have followed the precept of Stephen Leacock who wrote "The wise child, after the lemonade jug is empty, takes the lemons from the bottom of it and squeezes them into a still larger brew. So does the sagacious author ..." (Preface to *Moonbeams From the Larger Lunacy* (Gloucester, 1984). Many of the issues discussed here were previously presented in papers to the Scottish Archive Training School, Edinburgh, September 1992, the International Records Management Congress, Harare, September 1993, and the Royal College of Physicians and Surgeons, Glasgow, October 1994.
- 1 E. Linklater, *Juan in America* (Jonathan Cape, 1931), pp. 121-22.
- 2 S.J. Reiser, "Creating Form out of Mass, the Development of the Medical Record," in E. Mendelsohn, ed., *Transformation and Tradition in the Sciences* (Cambridge, 1984), p. 303 and Kings Fund, *Hospital Clinical Records* (London, 1985), p. 26.
- 3 Admissions registers of Glasgow Royal Infirmary and Victoria Infirmary (GGHB Archive HH67/56/1-117 and HB23/4/1-15).
- 4 Barbara L. Craig, "Hospital Records and Record-Keeping, c. 1850 - c. 1950: Part I: The Development of Records in Hospitals," *Archivaria* 29 (1989-90), p. 61.
- 5 See for example, L.S. Jacyna, "The Laboratory and the Clinic: The Impact of Pathology on Surgical Diagnosis in the Glasgow Western Infirmary, 1875-1910," *Bulletin of the History of Medicine* 62 (1988), pp. 384-406.

- 6 Barbara L. Craig, "The Role of Records and of Record-Keeping in the Development of the Modern Hospital in London, England, and Ontario, Canada, c. 1890 - c. 1940," *Bulletin of the History of Medicine* 65 (1991) p. 388 and S.J. Reiser, "Creating Form out of Mass, the Development of the Medical Record," in E. Mendelssohn, ed., *Transformation and Tradition*, p. 307.
- 7 Ward journals of Western Infirmary of Glasgow (GGHB Archive HH66/20/1-71).
- 8 Barbara L. Craig, "The Role of Records," pp. 383-6 and 391-2.
- 9 A.J. Cronin's fictional Scottish doctor, Dr. Finlay of Tannochobrae, was the principal character in a number of books and the inspiration for two series of television programmes. Some of the books are still in print, e.g., A.J. Cronin, *Short Stories From Dr. Finlay's Casebook* (Longman).
- 10 B. Benjamin, *Medical Records* (London, 1980), pp. 2 and 38-39.
- 11 J. Collett-White and K. Ward "Appraisal of mental hospital patient case files: the Bedfordshire Record Office experience," *Journal of the Society of Archivists* 15 (1994), pp. 181-86.
- 12 For example, David Cuthbertson's patient case folders relating to his work on diet, metabolism, and post-traumatic shock (GGHB Archive HH67/51/1-4).
- 13 Victoria Infirmary ward journals (GGHB Archive HB23/11/1-526).
- 14 Great Britain, H. M. Treasury, Organisation and Methods Division, *Scottish Branch Medical Records Work. Report of a study in Scottish hospitals*, 1959.
- 15 See for example E.A. Cheeseman, "Medical Record Linkage in Northern Ireland - Reconnaissance and Proposals with Particular Reference to Problems of Identification," in E.D. Acheson, ed., *Record Linkage in Medicine* (Edinburgh, 1968), p. 74 and Scottish Home and Health Department (SHHD), "Hospital Medical Records in Scotland," *Report of a Sub-Committee of the Standing Medical Advisory Committee of the Scottish Health Service Council* (Edinburgh, 1967).
- 16 Scottish Health Memorandum 70/1966 (GGHB Archive HB28/6/14).
- 17 Ward journals of Glasgow Western Infirmary (GGHB Archive HH66/11/1-36/39).
- 18 J.H. Mitchell, "A New Look at Hospital Case Records," p. 3.
- 19 There has been some change in recent years with the introduction of electronic Patient Administration Systems (PAS). These have not been applied retrospectively, however, and thus are only relevant to patient admissions from the late 1980s onwards.
- 20 J.H. Mitchell, "A New Look at Hospital Case Records," p. 3 and A.J. Hedley, "The Collection and Utilisation of Clinical Information," in J.C. Petrie and N. McIntyre, eds., *The Problem Orientated Medical Record* (Edinburgh, 1979), p. 2.
- 21 For striking examples see: J. Murchison, J.R. Barton, and A. Ferguson, "Analysis of cases incorrectly coded as inflammatory bowel disease in SHIPS," *Scottish Medical Journal* 136 (1991), pp. 136-38; G. McGonigal, C. McQuade, and B. Thomas, "Accuracy and completeness of Scottish mental hospital in-patient data," *Health Bulletin* 50 (1992), pp. 309-14; and, A.R. Patel, G. Gray, G.D. Lang, F.G.H. Baillie, L. Fleming, and G.M. Wilson "Scottish hospital morbidity data. Errors in diagnostic returns," *Health Bulletin* 34 (1976), pp. 215-20.
- 22 See G. Bowker and S. Leigh Star, "Discourse in the policy infrastructure: Crafting the International Classification of Diseases," paper presented at the conference entitled "Global perspectives on business information," 24-25 April 1992, University of Reading.
- 23 G. Bowker and S. Leigh Star, "Discourse in the policy infrastructure" and J. Durbin and A. Stuart, "An Experimental Comparison Between Coders," *Journal of Marketing* 19 (1954), pp. 54-66.
- 24 For a related argument regarding the preservation of clinical data assembled during the course of research see G. Davey Smith, "Increasing the accessibility of data," *British Medical Journal* 308 (1994), pp. 1519-20.
- 25 See for example J. McDonald, "The Case Against Microfilming," *American Archivist* 20 (1957), pp. 347-48; B. Benjamin, *Medical Records*, pp. 103-4 and 193; Kings Fund, *Hospital Clinical Records*, pp. 58-59, and J. Anderson, "Public Welfare Case Records: A Study of Archival Practices," *American Archivist* 43 (1980), pp. 176-77.
- 26 E. Higgs, "Particular Instance Papers: The Historical and Archival Dimensions," *Social History* 10 (1985), p. 92; I. Kearsey, "Some Problems in Placing Modern Medical Records in Public Archives," *Archives and Manuscripts* 17 (1989), p. 189 and Kings Fund, *Hospital Clinical Records*, p. 27.
- 27 If electronic summary data is not available it is possible that diagnostic hospital indexes may be a suitable substitute. If these are held in hard copy, as card index files, for example, electronic conversion via scanning should be considered.
- 28 P. Gillis, "The Case File. Problems of Acquisition and Access from the Federal Perspective," *Archivaria* 6 (1978), pp. 33-37 and E. McKay, "Random Sampling Techniques: A Method of Reducing Large Homogeneous Series in Congressional Papers," *American Archivist* 14 (1978), p. 284. In this regard also see I. Kearsey, "Some Problems," pp. 188-92; Ellen Scheinberg, "Case File Theory: Does It Work

- in Practice?" *Archivaria* 38 (Fall 1994) pp. 45-60, and Evelyn Kolish, "Sampling Methodology and its Application: An Illustration of the Tension Between Theory and Practice," *Archivaria* 38 (Fall 1994) pp. 61-73.
- 29 There are a number of issues involved here. First, before access to confidential medical data can be obtained an application must be lodged with an ethics committee. Removal of the records to another location will complicate this process and provide a further barrier to access. Second, administrative supporting documentation can be of vital importance in record interpretation. The scattering of related record groups will create additional complications for future users. Third, creating institutions should have the opportunity to receive credit for, and benefit from, research conducted on their resources. Indeed, if this does not occur it may be difficult to justify investment in data storage.
  - 30 F. Hull, *The Use of Sampling Techniques in the Retention of Records: A RAMP Study with Guidelines* (Paris, 1981), p. 15.
  - 31 A sampling frame is a list which contains a reference for every record in the series to be sampled. For hospital clinical records, a particularly useful frame is provided by the unit file number allocated by the hospital to each patient record. In practice, however, a wide variety of criteria can be employed as frames, for example, the year that the record was created or a list of patients' postcodes. No matter what type of frame is chosen it is important that every record in the series to be sampled should have a corresponding entry on the frame. As a rule of thumb the best frames do not list records in any particular order. Although clinical file numbers are not issued on a random basis, it is unlikely that consistent trends are present in the order that patients present at a hospital.
  - 32 I. Kearsey, "Some Problems in Placing," p. 190.
  - 33 This procedure involves allotting records to particular shelf ranges according to the last two digits of their unit file number. Imagine a medical records storage area, for example, where all files ending \*\*\*\*00 are stored on one shelf range, all ending \*\*\*\*01 on the next etc., up to \*\*\*\*99. Taking all of the records on any one of these shelf ranges is equivalent to drawing a one per cent systematic sample, selecting five ranges would be equivalent to drawing a five per cent sample, etc.
  - 34 W.G. Cochran, *Sampling Techniques* (New York, 1973), pp. 206-30; R. Parsons, *Statistical Analysis: A Decision Making Approach* (New York, 1974), p. 304; A.J. Wilburn, *Practical Sampling for Auditors* (New York, 1984) pp. 100-106; and Great Britain: PRO "The Sampling of Records for Statistical Use," *RAD Occasional Paper 5* (1975) pp. 1-2.
  - 35 See for example L. Steck and F. Blouin, "Hannah Lay & Company: Sampling the Records of a Century of Lumbering in Michigan," *American Archivist* 39 (1976), p. 18. Where this method is employed, it is recommended that records are also sampled for years where administrative reorganization occurred. F. Hull, *The Use of Sampling Techniques*, p. 13. In the context of health care provision this may prove an extremely complex and counter-productive exercise.
  - 36 I. Kearsey, "Some Problems in Placing," p. 191.
  - 37 See also F. Hull, *The Use of Sampling Techniques*, pp. 12-13. Hull cites the example of the appellate tribunals established under the *British Military Service Acts*, 1916. The record series consisted of registers and more detailed case files. The registers were kept *in toto*, but, the case files were systematically sampled. It was decided, however, to buttress this sample by retaining all information pertaining to conscientious objection.
  - 38 This would allow researchers to access inpatient episodes on the basis of the following criteria: name; unit number; hospital identification code; post-code; up to five ICD diagnostic codes per episode; up to three operation codes; cause of injury codes; date of birth and sex. Unfortunately, the only indexing mechanism available for pre-1961 records are the nominal hospital indexes maintained by individual hospitals. In the majority of cases these only list name, sex, and date-of-birth.
  - 39 Most hospitals in Glasgow use terminal digit filing (using numbers in the range 00-99). Our recommendation envisages removing all inactive patient files ending in five specified terminal numbers. This necessarily produces a five per cent sample. See also I. Kearsey, "Some problems of placing," pp. 191-92.
  - 40 H. Maxwell-Stewart, A. Tough, J.H. McColl, & J. Geyer-Kordesch, *Selecting Clinical Records for Long-Term Preservation: Problems and Procedures* Occasional Publication 5 (Glasgow, 1993).
  - 41 See for example C.O. Kohler, ed., *Cards, Databases and Medical Communication* (Berlin, 1992).
  - 42 See for example of the Registrar General of England and Wales, William Farr, in the Sixteenth Annual Report, 1856, Appendix 75-76, quoted in, *International Classification of Diseases* 1 Eighth Rev. (Geneva, 1967), p. viii.



- 43 Optical discs, for example, can only be accessed by means of appropriate hardware and software. If they are to be preserved, it will be necessary either to keep a "museum" of appropriate hardware and software with their related manuals (plus technical staff who possess the necessary maintenance skills) or to undertake regular conversion of data to new hardware and software systems. Current experience has shown that this can be an extremely expensive and complex task. M. Anderson, "The Preservation of Machine-Readable Data for Secondary Analysis," *Archives* 17 (1985), p. 79 and E. Higgs, "Machine-Readable Records, Archives and Historical Memory," *History and Computing* 4 (1992), p. 183.
- 44 P. Lewinson, "Archival Sampling," *American Archivist* 20 (1957) p. 296.