
Designing Medical Archives Programs in the United States¹

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My first introduction to medical archives was not in a repository that had many of the characteristics we now think of as desirable in a well-run archive. The documents in which I was interested for research on my Ph.D. were the records of a late eighteenth-century professional medical society. They were housed in the Academy of Medicine in Paris. The Academy was a forum for meetings of the élite amongst French physicians and had been founded in 1820. Located in a nineteenth-century building, it incorporated a library for use of the academicians and collections of materials relating to its history as an institution and the activities of its members.

Access was difficult: the prospective user had first to persuade the porter to open the street door of the building and allow entry, and then negotiate the back corridors and stairs largely in the dark. Illumination was by those pernicious French lights connected to timers that turn them off after 20 seconds. The keeper of the archives saw herself as the guardian of treasures to be protected rather than the

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facilitator of use. No inventory existed nor any finding guides and I, as researcher, had 115 boxes of uncatalogued materials randomly ordered to work through. Despite the negative features of difficulty of access and use, this repository had, in retrospect, one redeeming aspect that outweighed the rest. The records had been saved and their existence made possible studies of medical research, education, and the profession in late eighteenth-century France. Our understanding of twentieth-century medical care and research will be immeasurably diminished if we do not first make the commitment to save the materials and then decide how to organize them and give access. How best this should be achieved is the matter for discussion.

In this paper I have been asked to describe the collecting and organizational strategies that have been adopted by several different medical archival repositories in the United States. As will be seen, there is no one ideal model. Different circumstances and institutions impinge on different outcomes. But my hope is that review of these archives will provide examples for a broader discussion of the issues facing all those engaged in preserving the documentation of biomedicine and patient records in Australia and elsewhere that others have described. A comparative perspective can be beneficial. As all who are involved in development and management of archives know, the commitment to save is only the first step in confronting a series of issues facing medical archives as we approach the year 2000.

The late 1980s and 1990s have seen a period of questioning of whether accepted approaches to the documentation of modern medicine will preserve the materials needed to develop a rounded view of medicine in this century, particularly in its second half. Some of the questions raised include the following: Is it sufficient if individual libraries and repositories collect the records of distinguished or prominent physicians and scientists, and in some instances, the records of professional and institutional medical organizations and institutions, or should other strategies be investigated? Developments in medicine are now occurring in a wide variety of settings, including universities, hospitals, research institutions, pharmaceutical and biotechnology companies, as well as in individual and group practices and insurance companies. How can collections from these be organized? Research and patient care are now often the result of the work of a team, rather than the product of individual effort. How does this affect documentation? In addition, the forms of material used in medicine to record data have expanded from paper records to include

photographs, slides, images from X-rays, CAT scans, MRIs, and the newer imaging technologies, films and videotapes, audiotapes, and electronic records. All require separate attention and management. The volume of material available and its varying character and quality suggest that a strategy of just saving more will not work. What is needed are ways to apply strategic thinking to ensure that representative samples of all relevant materials are collected.

The first example of a twentieth-century medical archive that I wish to discuss is that housed in the History of Medicine Division of the National Library of Medicine, Bethesda, Maryland. The National Library of Medicine, known as the NLM, describes itself as the world's largest medical library. It is located on the campus of the National Institutes of Health in the Washington suburbs and is funded by the United States government. Its goal has been diffusion of medical knowledge via traditional and electronic means to medical professionals and institutions. But this mission is expanding. One important development is that its searchable database *Medline*, previously only accessible by subscription to health professionals, has been made available to the public. The NLM's History of Medicine Division is the largest repository in America for books and other printed materials relating to the development of medicine over the centuries. It also comprises a manuscripts and oral history collection. Of the over 1,000 manuscripts in the collection (some 3,000 linear feet), most are material from 1600 on, and the collections are particularly rich in eighteenth- and nineteenth-century American and British materials and in twentieth-century American materials.

There was no special program in the earlier part of the Library's history to acquire manuscript materials; such deposits as were made were part of the general collecting of historical materials. In the 1960s, the National Library of Medicine embarked on an active acquisitions program for twentieth-century materials. Selected individuals who had made significant contributions to contemporary medicine or whose personal papers would contribute to an understanding of modern medicine, were encouraged to deposit their papers at the National Library of Medicine. Noteworthy acquisitions included the papers of medical figures such as Stanhope Bayne-Jones, Alan Gregg, Chauncey Leake, A. Baird Hastings, and Julius Richmond. The archives of a number of national professional societies, including the American Surgical Association, the American Society for Clinical Investigation, the Medical Library Association, and the Alpha Omega Alpha Honor

Medical Society were also acquired and form part of the manuscript collections.

Current collecting priorities are: 1) papers of individuals who have made landmark contributions to the biomedical sciences; 2) personal papers which contribute to an understanding of or which document the practice of modern medicine; 3) records of national medical organizations and professional societies; and 4) personal papers and other records of past National Library of Medicine officials. Primary emphasis is placed on collecting North American manuscript materials, although the NLM does not rule out collecting materials from other parts of the world.

The NLM has a broad definition of formats of material that it will collect including: hand- or typewritten or computer generated documents; originals or copies of letters; printed matter that forms an integral part of a collection; photographs and other visual materials; audiotapes and other audio recordings; artifacts and other memorabilia if of permanent historical interest; and microfilm copies of manuscripts found in other repositories.

The NLM has recognized that by itself it cannot collect all manuscript records documenting the development of biomedical science in America and that it needs to cooperate with other medical manuscript collections. It also does not solicit materials for which there is a more appropriate repository. If, for example, an individual medical scientist has had a long association with a university and that university has an active archives program, the NLM would normally defer to the university program. If an individual has not been associated with one single institution, the NLM may consider the acquisition of his or her papers.

Most manuscript collections are donated to the NLM and not purchased. While the library has found that the initial expenses of accepting a collection may be modest, often primarily consisting of the expenses of boxing up and transport to the Library of the materials, the costs of organizing and storing a collection are quite high. Standard estimates are that it takes twenty to thirty-six hours per linear foot to process manuscript materials. Despite being a national library, in its History of Medicine Division, the NLM has only one curator for modern manuscripts, who has a couple of assistants. There is also only one individual to handle both the prints and photographs collections and the film and video collections. In certain instances, to get materials processed and catalogued, the Library has to look for

outside support for the organization of material and contractors have to be hired. Access to the collections in the NLM is open to registered users of the library. Time limitations on access to manuscript materials can be placed by donors³.

In a number of ways this archive is traditional in its outlook. Its acquisition program, although more activist than previously, is better geared to respond to opportunities that are presented by offers of donations than in strategizing to augment and enhance its holdings. In a sense, it is growth by accretion. Moreover, although at first sight it would seem a plus to be part of a large federally funded library, that library's emphasis on high speed electronic searching and delivery of up-to-date medical information to a network of users around the United States and internationally, promotes an administrative outlook that is not necessarily beneficial to medical archive development. The present and future may well have preference over the past and the expertise and benefits of maintaining staff professionally trained in archival management continually have to be emphasized. The difficulties of limited staffing in the History of Medicine Division and the need to seek outside funding for processing materials can also create problems in cataloguing and making available archival materials to researchers, and make difficult the initiation of innovative projects such as digitizing records and investigating web access to them.

To turn now to a second example of the documentation of twentieth-century medicine in the United States. As I have noted, the National Library of Medicine is located on the campus of the National Institutes of Health, which is the largest federal biomedical research institution in the country. The activities carried out in Bethesda and the funding the NIH has provided to institutions and individuals around the nation have been one of the primary reasons, perhaps the primary reason according to some, for the accomplishments of American medical science in the second half of the twentieth century. Yet, perhaps surprisingly, the NLM is not the repository for documentation of the medical research in the laboratories and the patient care and treatment in the research hospital, known as the Clinical Center, that are part of the NIH. The reason for this is that the National Archives of the United States is the designated location for deposit of all materials relating to the activities of federal agencies.

In terms of archival location and resources, this would seem on the face of it to have a number of advantages. The National Archives are well staffed and funded and have recently opened a magnificent new

building in College Park, an area in the Maryland suburbs of Washington, D.C. Moreover, materials generated by federal employees are in the public domain and are not the employees' personal property. The researcher might reasonably expect that there would be in place established policies for *organization, collection, and disposition* of materials generated by the NIH. And, in fact, for all U.S. government agencies, fully developed records management policies have been promulgated concerning retention and transport of materials to the National Archives. In certain areas of NIH operations, particularly administrative ones, these policies have been effective in preserving records of decisions made and the ways in which they were implemented. (I should mention in passing that the volume of records generated by U.S. government agencies is so voluminous that cataloguing and disposition may be considerably delayed.) But what is not being well preserved are details of who worked at the NIH and when (there are, for instance, no comprehensive biographical files) and detailed records of laboratory and clinical research are not being maintained.

Several factors contribute to this situation: One is the decentralized nature of the NIH with research being conducted in 20 or so different institutes; Two is the autonomy and independence of the various institutes and of the laboratories within them. Each director of an institute, for instance, presents his or her own case to the U.S. Congress for that institute's funding; Three is the steadily changing population of scientists and researchers who work at the NIH. The affiliation of many scientists is short term and they move on to other institutions, taking records with them, without having differentiated what should be left behind; Four is that although each institute has a designated records manager, there has been no concerted program to keep reminding researchers and clinicians to maintain the documentation either of the clinical trials conducted under research protocols at the NIH hospital or of the records of laboratory research. A once a year formal notification fulfils official specifications. In an example of which I am aware personally, the patient record for the first case of AIDS treated at the NIH hospital under a research protocol has simply disappeared; Five, space is often at a premium in NIH laboratories and leads to disposition of materials relating to research perceived as unproductive. Another reason for the non-retention of records has been the passing of the 1986 Freedom of Information Act, which allows any citizen to request documents generated by federal employees.

Sometimes well meaning policies designed to allow greater access to records of government activities backfire. Some scientists faced with extensive requests for laboratory reports, notebooks, and early results, changed their methods of documenting what occurred in the laboratory. AIDS research at the NIH again provides an example where the need for public information and the preliminary nature of research results available were not in accord. Another factor in whether laboratory or clinical research findings are maintained is the medical scientists' perception that what counts is what is published, not what came before. Many are not interested in documenting the process of science, the blind alleys, the sources of ideas, so much as the product. In the minds of many scientists, most of the materials generated leading up to public announcements of results through publication should be thrown out.

The NIH offers an example of an institution about which there is little debate that a record of its contributions to the development of biomedical science should be preserved and one which is subject to well-thought out policies for federal agencies for retention and disposition of records. But, as I have tried to indicate, for a combination of reasons, this has not ensured good documentation of many of the clinical and research activities in its laboratories and hospital. Having a documentation strategy in place does not guarantee that it will be followed. Hands-on follow-up and personal intervention are needed to ensure that such a strategy is carried out and the help of the medical and scientific community must be enlisted in preserving research records.

My third example of a major United States medical archive is one connected with an academic medical centre composed of a teaching hospital, a medical school, a school of public health, and a school of nursing. The Alan Mason Chesney Medical Archives of the Johns Hopkins Medical Institutions in Baltimore, Maryland, is one of the most dynamic repositories in the nation⁴. Named after a former dean who located many of the early records and then wrote a three-volume history of the Johns Hopkins Hospital and School of Medicine, the Chesney archives had small beginnings in 1978. In the twenty years since then it has developed into the official archival repository of all divisions of the Johns Hopkins Medical Institutions, with holdings from

4. See Nancy McCall and Lisa A. Mix (eds.), *Designing Archival Programs to Advance Knowledge in the Health Fields* (Baltimore and London: Johns Hopkins University Press, 1995).

the mid-nineteenth century to the present. These include not only extensive institutional records and documents including patient records, but also substantial collections of personal papers and materials from individuals associated with the Medical Institutions. For instance, there are now 221 personal paper collections which include correspondence, laboratory notebooks, clinical and research data, course notebooks, financial records, and photographs. The collections of visual materials include in addition to over 30,000 photographs of laboratories, hospital activities, scientific and medical equipment, and individuals and groups, architectural drawings relating to the buildings, and about 100 films and videotapes documenting lectures, ceremonies, and medical procedures. The Chesney archives have also developed biographical files of over 10,000 individuals who were or are associated with the Hopkins Hospital and the Schools of Medicine, Hygiene and Public Health, and Nursing.

As part of its responsibilities, the Chesney Medical Archives has a contemporary records program. This covers the organization and management of administrative records of the Medical Institutions from 1956 to the present. Services provided include storage, document retrieval, and records scheduling. Archives staff work actively with departments participating in this program to appraise and retain records. Access to this collection is limited to specially designated staff of the offices where the records came from. Part of the archival responsibility is to determine which records in this collection should be scheduled for long term retention in the Medical Archives and which, after a certain time span, can be discarded.

The Chesney Archives is unusual in that it also is responsible for the maintenance of items that in other circumstances are often placed in a separate medical museum, such as medical and surgical instruments and equipment, as well as decorative objects and furniture.

The growth and recognition attained by the Alan Mason Chesney Archives as an archive relating to an academic medical center are a tribute to the hard work of its dedicated staff and their leadership in tackling issues relating to storage, documentation strategy, and access confronting medical archives at the end of the twentieth century. The Chesney Archives have also benefited from the patronage of physicians who were deans of the medical school and chiefs of departments who had a strong interest in preserving the records of their institution and commemorating its history. This concern has been instrumental in raising the profile of the archives within the institution and in obtaining

funding for its activities. In this particular instance, archivists and physicians and scientists working in tandem have contributed to the result. It offers a contrast to the interactions characteristic of a library governed by federal bureaucratic policies such as the National Library of Medicine. Moreover, the existence of the archive and use of its resources by researchers leads to more widespread interest and further funding.

Two recent projects of the Chesney Archives should be described briefly because they relate to issues being examined in this conference. One is an exploration of the issues relating to digitization and internet communication of clinical and experimental records. Two sets of records from Johns Hopkins were used as case studies: one, the patient records of the Brady Urological Institute (1915-1973) relating to patients who had been diagnosed with posterior urethral valves (a serious congenital condition); two, experimental and observational data from the Psychobiology Laboratory of Hopkins relating to the grasp reflex, periodic phenomena in animals and man, and neuro-endocrine study of spontaneous bodily activity (1920-1975). The case study approach allowed issues relating to document preparation, imaging, and data entry to be explored including costs of outsourcing, access to material on the internet, ethical implications, and copyright and intellectual property issues. The results obtained so far indicate, among other things, that a broad range of clinicians, scientists, social scientists, historians, and archivists need to be involved in developing appraisal criteria in the selection of materials to be digitized.

The second project was an outcome of the first. It was the holding of the first international cyberconference in July 1996 on the psychobiology of Curt P. Richter. The purpose was to explore how the research data that Richter collected during his many years at Hopkins could be preserved and used in ongoing teaching and research activities, thus stimulating interest in the ways primary data from other research laboratories might be recycled for future use in teaching and research.

In several ways, the Alan Mason Chesney archives are breaking new ground not only in archival collection and management, but in investigation of relevance that clinical records and medical information can have for tracing the relationship of changing treatments and outcomes. Support is provided for current activities of the Johns Hopkins Medical Institutions as well as recognition of past achievements and contributions.

These short descriptions of medical archival activity in the United States could be supplemented by numerous others but length of paper allotted and other constraints prevent this. In conclusion, let me reiterate issues concerning medical archives already raised by the examples described in this paper. The first is that for a successful medical archive program there is a need for a cooperative endeavour. Time and energy have to be spent in educational outreach by archivists and historians to physicians, scientists, and administrators. The second is that collecting alone is not sufficient to develop an archive. There is a need to confront the problems relating to the ever increasing quantity of records and also of new formats. The third is that a pragmatic approach is necessary. Archivists have to keep working with particular situations and groups on an intensive basis. The installation of overarching policies on records keeping and management may still not capture the materials that should be kept.

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