

Problems of Confidentiality in the Administration of Personal Case Records

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THE ORGANIZATION AND PROVISION of health and welfare services have become major societal functions in the United States during the past forty years. As the fields have expanded and grown complex, there has been a corresponding increase in the volume of records generated in all phases of their delivery systems. One document-type characteristic of the health and welfare fields, the personal case record, has proliferated. Administration of case records is difficult because they contain data about individuals. Depending on the purpose for which the record was created, and the date when it was compiled, the case record may include age, sex, religious preference, medical history, legal and financial status, marriage, family and social relationships, and residence and employment patterns, all of which may be supplemented by test results, investigations, diagnoses, and notations of courses of therapy or intervention. Because of this sensitive information, case records have been considered confidential by health and welfare professionals, who traditionally restrict access to a select group of colleagues, presumably in the best interests of patients and clients.

Records practices are changing, however, under the impact of internal developments in the health and welfare fields and altered social attitudes. The systems approach to administration and planning demands wide dissemination of information, while increased specialization within the fields has necessitated broader sharing of data among professionals. Large-scale programs of insurance, compensation, and assistance have created a substantial class of "third parties" with justiciable claims for access to

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records formerly regarded as the exclusive property of the creating institution or professional.¹ Furthermore, the individual record subject (patient or client) has been increasingly successful in asserting his right of access to his own records, a concept previously unthinkable.²

Types of research in case records have also changed, and the research community has expanded to include the behavioral scientist and the social historian.³ Medical professionals are aware of this new demand for access to information for uses other than the traditional morbidity and mortality studies. A recent publication of the American Hospital Association lists, in addition to the hospital staff, nine categories of legitimate users of medical records,⁴ and the American Medical Association reports that twenty-four states have passed laws authorizing the use of hospital records in "research that will benefit society as a whole, provided the identity of individual patients is protected."⁵

While these trends have broadened access to records and furthered their utilization in research, the increasing cost of records maintenance has resulted in a tendency to limit drastically the retention period. As the number of patients and clients grows, the volume of records reaches critical proportions in many institutions. Two recent studies have concluded that virtually all uses of medical records are accommodated by a retention period of only fifteen years following termination of services.⁶ The Illinois Department of Public Welfare has ac-

¹ American Hospital Association, *Hospital Medical Records: Guidelines for Their Use and the Release of Medical Information* (Chicago: American Hospital Association, 1972), pp. 1-2; Eric W. Springer, *Automated Medical Records and the Law* (Pittsburgh: Health Law Center, 1971), p. 2.

² For general discussion of the legal rights of patients to their records, see Larry Fleischer, "The Ownership of Hospital Records and Roentgenograms," *Illinois Continuing Legal Education* 4(1966):73-77. A recent government survey reports that nine states (including Illinois) allow some form of access, either by the patient or his attorney, to medical records, without litigation. See U.S., Department of Health, Education, and Welfare, *Medical Malpractice: Report of the Secretary's Commission on Medical Malpractice*, 2 vols., Dept. HEW Pub. No. (OS) 73-88 (January 16, 1973) 1:76.

³ For research illustrative of the uses of case records, see Thomas McKeown, "A Sociological Approach to the History of Medicine," *Medical History* 14(1970):342-51; Barbara Gordon and Helen Rehr, "Selectivity Biases in the Delivery of Hospital Social Service," *Social Service Review* 43(1969):35-41.

⁴ American Hospital Association, *Hospital Medical Records*, p. 31. Categories included public health and welfare personnel engaged in facility planning and demographics, private social agency personnel studying the community, and graduate students in public health and social work.

⁵ American Medical Association, Board of Trustees, "Release of Information from Hospital Medical Records," Report X (A-72), p. 5.

⁶ Illinois Association of Medical Record Librarians, "Retaining Records: How Long?" *Medical Record News* 34(1963):9-12. Kenneth R. Wagner, "Developing a Record Retention Schedule for a Medical Clinic," *Medical Group Management* 20(1973):11-17.

cepted a twenty-five-year retention period for all medical-clinical records except those specifically exempt on grounds of unusual interest or high degree of probability for future litigation.⁷ The basis for these relatively short retention periods is that previous research requests do not justify extended retention. This projection of past research needs disregards current trends, especially those stimulated by computer capabilities for analysis of vast amounts of raw data. Practices which are promoted in the interest of efficient records management may be antithetical to scholarship. In these cases the archivist must overcome a certain reluctance to deal with confidentiality issues posed by personal case records in order to preserve them for future uses. The archivist should exercise a longer-range perspective than that of the hospital or agency records officer in assessing the permanent value of case records. At the same time, the archivist must recognize that in assuming custody over case records he becomes responsible for administering materials in which two social values—the public's "right to know" and the individual's personal privacy—come into potential conflict.

Public acceptance of the use of case records for purposes other than the provision of services to patients and clients is conditional upon the maintenance of individual privacy. Basically, the doctrine of privacy assumes that the individual has a right to a certain "social space" free from undue interference from the larger society of which he is a part.⁸ It may become necessary or desirable for a person to share information from this intimate sphere of life, but the disclosure of it is based on the assumption that the information will remain confidential. Data revealed in a professional relationship with physician, therapist, social worker, and the like, do not become the property of the professionals, and participation in such a relationship does not imply consent to any and every use that might subsequently be made of the information. The law recognizes that a person may suffer damage to his reputation and self-esteem from the public disclosure of private facts and provides the remedy of suit for invasion of privacy.⁹

⁷ Virginia Lake, "Pioneering in the Control of Medical-Clinical Case Records," *American Archivist* 24(1961):303-07.

⁸ The formulation of "privacy" as a barrier to information exchange is discussed by sociologist Edward Shils in "Privacy: Its Constitution and Vicissitudes," *Law and Contemporary Problems* 31(1966):281-318. The entire issue [vol. 31, no. 2 (spring 1966)] is devoted to a legal and theoretical examination of privacy.

⁹ For an exhaustive treatment of privacy, see Alan F. Westin, *Privacy and Freedom*, copyright 1967, by Association of the Bar of the City of New York (London: The Bodley Head, 1970); *On Record: Files and Dossiers in American Life*, Stanton Wheeler, ed. (New

An archival collection of personal case records involves record compiler, subject, and user, each with a particular viewpoint on the proper balance between access to and restriction of data. One's perspective on responsible use of confidential materials varies with one's relationship to those materials. Health and welfare professionals have addressed the privacy issue with varying degrees of success.¹⁰ The archivist not only must develop standards to accommodate donor, record subject, and researcher, he also must protect his repository against lawsuits arising from careless or unscrupulous use of data in case records.¹¹ A viable standard allowing use of confidential information for administration, planning, and research would assure that subjects of the records would not be identified in contexts harmful or damaging to them. A relatively simple approach would be the obliteration of names, addresses, and similar data from the case records. This would guarantee that researchers could not present these data, but it would also do a disservice to those attempting to correlate information from several agencies or systems, to those attempting longitudinal studies of individuals, and to those personal users seeking to learn such matters as age, marital status, or health treatment. On the other hand, if individually identifiable data are allowed to remain as part of case records, how does the archivist enforce standards of confidentiality? It is meaningless to announce policy if it cannot be implemented. What can archivists actually do to fulfill the obligation they incur in accessioning case records?

Judging from the literature on the subject, archivists have only recently addressed themselves to the administration of case records.¹² In the absence of substantial published treatment of the subject, a small survey was undertaken in June 1973. A

York: Russell Sage Foundation, 1969) is an up-date and extension of the Westin volume. Louis Lusky, in "Invasion of Privacy: A Clarification of Concepts," *Political Science Quarterly* 87(1972):192-209, offers a formulation of privacy in sharp contrast to Westin's.

¹⁰ Joint Commission on Accreditation of Hospitals, *Accreditation Manual for Hospitals* (Chicago: Joint Commission on Accreditation of Hospitals, 1971), pp. 91-96; American Hospital Association, *Hospital Medical Records*; National Conference of Lawyers and Social Workers, *Confidential and Privileged Communications: Guidelines for Lawyers and Social Workers*, Publication no. 7 (New York: National Conference of Lawyers and Social Workers, 1968).

¹¹ A repository furnishing material to a researcher may incur liability as "general publisher" to lawsuits arising from published research. See Noel C. Stevenson, "Genealogy and the Right of Privacy," *American Genealogist* 25(1948):145-52.

¹² See Vaughn D. Bornet, "The Manuscripts of Social Welfare," *American Archivist* 23(1960):33-48; Virginia Lake, "Pioneering in Controls," (1961); and James F. Gill and Thornton W. Mitchell, "Ohio—Disposition of Medical Records in State Mental Hospitals," *American Archivist* 26(1963):371-78.

questionnaire was sent to sixteen repositories identified either in the national manuscript indexes or by archivist colleagues as possessing collections of the types in which case record series are often found. Each repository was asked what types of their collections included case record series, what kind of restrictions were developed regarding access, what procedures were employed to enforce these restrictions, and whether the repository had experienced legal problems in administering case records. Fifteen institutions returned the questionnaire, and the commentary which follows is based on their responses.

Case record series occur in a wide variety of collections: records of public and private welfare agencies; social settlements; clinics, hospitals and public health agencies; juvenile homes and residential and special schools; adoption agencies; public-interest organizations such as hygiene leagues; labor-union grievance and compensation boards; religious and fraternal charitable enterprises; self-help organizations; and the personal papers of physicians, social workers, educators, researchers, and public officials. Not surprisingly, in view of the relatively recent interest in collecting material in the health and welfare fields, no institution had formally worked out a policy statement covering acquisition, custody, and access to case records from a theoretical and legal perspective, although several repositories are in the process of drawing up such a statement. In general, case records are received in repositories with donor-imposed restrictions on access, the most common requiring the donor's permission to use the records. Some donors close case records to all users for a specified time period after which, presumably, the records are available to anyone. Whatever restrictions exist are generally incorporated into the document negotiated to cover the deposit of material. Those repositories functioning as state archives, or holding records of public agencies, are under state statutory regulation as to the use of confidential material; such statutes vary widely. Several repositories reported imposing additional restrictions on use, primarily in cases where the archivist had doubts about researcher sophistication in handling sensitive material.

If the anonymity of record subjects is to be maintained in publication or teaching, the enforcement of appropriate standards cannot end with the granting of research access. The archivist must take measures to effect compliance, a function that appears to have received insufficient attention among my respondents. Roughly one-third reported instituting procedures to safeguard confidentiality. Of these, the majority re-

quire the researcher to sign some form of agreement promising confidentiality in his treatment of case records; one repository has established a policy of prepublication review of manuscripts; one repository occasionally reviews research notes; and two have taken steps to conceal the identity of case record subjects either through obliteration of names or by coding. Only two institutions reported discussing confidentiality problems with researchers, although I suspect that this practice is more widespread than the questionnaire revealed. Nonetheless, in view of the acknowledged difficulty that researchers have had in formulating codes of ethics for research situations, it is not possible for the archivist to abandon his responsibility for preserving confidentiality in hopes that researchers will all have high standards!¹³

None of the institutions reported experiencing legal difficulties with their case record holdings, but this, in my opinion, reflects the recent nature of the acquisitions and the limited use made of them so far. The possibility of legal action exists in several situations:

Subpoena. The actual physical custody of case records can involve the archivist in legal tangles if records are subpoenaed for legislative, administrative, or judicial proceedings. Faced with an order to produce records he considers confidential, the archivist has two alternatives: deliver the records as ordered or resist the subpoena. The first course may be the only one realistically available to the archivist, especially if the repository is part of an institution such as a state university, which considers compliance with subpoena obligatory. In such circumstances the donor (and the record subject if possible) should be informed of the action. The archivist should be as exclusive as possible in complying with the order; he should err on the side of producing too little documentation rather than too much. In some cases, summaries prepared by the archivist may be acceptable in lieu of the records themselves. Security copies of any material supplied should be made and retained by the repository.

Essentially, resisting subpoena involves convincing a court that the subpoena was improperly issued, on grounds that disclosure of confidential information is prohibited by law. The relevant statute might be a public records act specifically exempting certain classes of records from disclosure or a licensing law

¹³ Ethics in research situations are treated in "Social Research and Privileged Data," *Valparaiso University Law Review* 4(1970):373-78, and in Oscar M. Ruebhausen and Orville G. Brim, Jr., "Privacy and Behavioral Research," *American Psychologist* 21(1966):423-37.

requiring that licensees (such as hospitals) keep records confidential. Such statutes vary from state to state.¹⁴ Some shield such information completely, allowing it to be used only for the purpose for which it was obtained (e.g., Connecticut); others allow the court to decide whether the protection of confidentiality takes precedence over the need for information in a particular case (e.g., Kansas); and still others, including Illinois, prohibit the public from obtaining such information but do not limit disclosure forced by the judiciary. A defense of case records based on the appropriate statute offers a reasonable chance of success, if the repository will undertake it.

No case has yet been litigated in which the archivist contended that the terms of the deposit agreement between donor and repository constituted a contract which the archivist's professional code bound him to perform ("he should carefully observe any established policies restricting the use of records").¹⁵ Successful assertion of such a vaguely worded professional ethic would be indeed surprising. Nonetheless, if a repository became involved in resisting a subpoena on other grounds, it would certainly be worth making the argument as a small beginning toward establishing some legal status for an archivist's professional ethics.

The archivist is not protected by the legal doctrine of privileged communication, whereby confidential information revealed in the course of a professional relationship is exempt from forced disclosure as testimony.¹⁶ This privilege belongs to the client in a professional relationship, not to the professional. An archivist cannot claim that the records in his custody are privileged communications and refuse to deliver them. In any state where privileged communication is recognized either by statute or judicial interpretation, only the individual subject of the records can assert his right to block disclosure of the content of his own record in court.¹⁷ If, however, the patient or client waives this right (either expressly or implicitly through instigating certain types of litigation) the archivist must produce the record. He should, however, deliver it directly to the court, not

¹⁴ "The Social Worker-Client Relationship and Privileged Communications," *Washington University Law Quarterly* (1965):362-79.

¹⁵ "The Archivist's Code," *American Archivist* 18(1955):307-08.

¹⁶ Gerd Schroeter, "Protection of Confidentiality in the Courts: the Professions," *Social Problems* 16(1969):367-85.

¹⁷ Thirty-one states expressly recognize physician-patient privilege. (See J. W. Wade, "Defamation and the Right of Privacy," *Vanderbilt Law Review* 15[1962]:1093.) New York has recently granted privilege to licensed social worker-client relations. (See Selma Arnold, "Confidential Communications and the Social Worker," *Social Work* 15[1970]:61-67.)

to the litigant or his attorney, in order to insure that the record appears exactly as it did while in the archivist's custody.

Libel and invasion of privacy. These related torts are invasions of personal rights which are actionable at law without the requirement of specific proof of damage suffered.¹⁸ Libel encompasses any false statement which brings a person into public hatred, contempt, or ridicule; causes him to be shunned; or injures him in business or occupation. The truth of any statement, provided it was not made with malicious intent, is defense against allegations of libel. Invasion of privacy, however, deals with statements that are demonstrably true but are offensive to persons of reasonable sensitivity. The widespread disclosure (such as publication) of personal information (facts which are not a matter of public record) is actionable, and truth is no defense. Although the opportunity for an individual to sue after these torts are committed ceases with his death (a relative or associate cannot sue on behalf of the deceased), case records often include information on children, spouses, relatives, friends, and associates, all of whom could sue on their own behalf. Thus the archivist must exercise caution, even when the case records are of such vintage that the prime record-subjects are assuredly deceased.

Competent legal advice is a necessity in administering case records. Several of the respondents to my questionnaire reported seeking counsel in establishing policy, but I believe that all repositories handling such records should consult with counsel to ascertain the relevant statutes and judicial interpretations in their jurisdiction as well as to formalize procedures to be followed in disposing of any legal problems which arise. It is best to anticipate legal difficulties in order to avoid being forced to deal with situations on an *ad hoc* basis.

The experience of the Manuscript Section of the University of Illinois Library at Chicago Circle in administering case records has been with social welfare collections which represent approximately 10 percent of our holdings. Case records are found in personal papers of social workers, parole officers, and the like, but the majority occur in records of child welfare agencies such as the Illinois Humane Society and the Juvenile Protective Association, in residential service organizations such as the Central Baptist Children's Home and the Cathedral Shelter, and in

¹⁸ Roy D. Weinberg, *Confidential and Other Privileged Communications*, Legal Almanac Series no. 61 (Dobbs Ferry, New York: Oceana Publications, Inc., 1967) is a comprehensive work on privilege with a careful explanation of the laws of defamation and invasion of privacy.

benevolent associations such as the German Aid Society. Most of these accessions are covered by a standard deed of gift transferring title to the board of trustees of the University of Illinois with the restriction that

The University of Illinois agrees that, in making available to researchers using its manuscript collection any of the case studies hereunder transferred to the University by the donor, it will advise such researchers that the names of the individuals with whom such case studies are concerned are to be held in strict confidence, that no notes of such names are to be made, and that such names will not be used by the researcher, nor will they be permitted to appear in any publication resulting from the research. The University further agrees that it will not itself release the names of any individuals identified in said case studies except with the written approval of the donor.

No collection has been accessioned with an absolute prohibition on use of the case record series. However, we have not been entirely successful in preserving case records; in one instance the donor destroyed all the case records before depositing the collection in the Manuscript Section despite our efforts to convince her of their research value.

The library has been served with subpoena for manuscript materials only once since the section was established in 1966. A patient, commencing a lawsuit, wanted her medical records from the dispensary operated by a settlement house whose records we hold. The Manuscript Section had not accessioned these records; at that time we did not accept medical records. If the records had been in our custody, no subpoena would have been necessary for the patient to gain access to her own file. Obviously, we were unable to comply with the order. Nonetheless, the reaction of university officials to the subpoena for records demonstrated their willingness to comply readily. The Manuscript Section concluded that there was little likelihood of university support for resisting any future subpoenas on grounds of confidentiality.¹⁹

In an attempt to inform both donors and researchers of the concepts and procedures we employ in administering case records, the Manuscript Section has written a policy statement

¹⁹ *Illinois Ann. Stat.* Ch. 51, par. 5-1, 5-2, and 71 recognize a wide range of privileged communications, including physician-patient, priest-penitent, psychologist-patient, and accountant-client, but these privileges are not absolute. Confidential communications may be introduced in a variety of cases such as malpractice suits, homicide, and child abuse. Since the decisions rendered under the right of privacy in Illinois do not support a prohibition against subpoena (See James E. Starrs, "The Right of Privacy Action in Illinois," *Illinois Continuing Legal Education* 1[1963]:41-45) it seems likely that case records could be subpoenaed from an archival repository.

governing acquisition, custody, and access to confidential materials, emphasizing preservation of the anonymity of record subjects. The chief concerns of the policy are detailed specification of extent and time-period of restrictions; maintenance of confidentiality during technical processing and storage; and procedures governing research use. Policy on access follows.

Any person wishing to use case records must make application, identifying himself and stating his research purpose. In this application he will agree to maintain the confidentiality of the subjects and all persons mentioned in case records. The application will be reviewed by the Manuscript Librarian (or a designate), who will inform the applicant of the restrictions applicable to the collection requested.

All research notes are subject to review by the Manuscript Librarian for compliance with the applicable restrictions.

A copy of any publication resulting from the research shall be provided by the user to the Manuscript Section.

A researcher seeking access to case records is required to sign a special request form (in addition to the standard reader's register which obligates the user to observe common law and literary property rights and to refrain from libel). The request form, used as a basis for an interview with the archivist, elicits basic information about the researcher's background and proposed project. The researcher agrees to

preserve the confidentiality of these records by refraining from making any public or private disclosure of information contained in these case records which would identify any person mentioned as a subject of such records. I shall make no notation of the names of individuals with whom such case records are concerned, and such names will not be used for teaching purposes, nor will they appear in any publication resulting from this research.

He agrees also to "hold harmless and indemnify The Board of Trustees of The University of Illinois, its officers, agents or employees, for any loss or damage to them occasioned by the release of the informational content of these records."

The archivist reviewing the application is responsible for informing the researcher of the restrictions applicable to the records he seeks. The archivist may also request supporting documentation of the researcher's credentials, such as signature of a dissertation advisor. The researcher is alerted to his possible financial liability in the event of a lawsuit arising from his use of confidential materials. Research notes are subject to review by the archivist.

These procedures are not designed to harass the researcher or to force the archivist to judge the validity of the researcher's conclusions, but rather to bring the archivist and the researcher into close contact during several stages of the work. It obviously is not possible to fulfill all these conditions in every instance. Researchers do not always write ahead to request information and inquire about restrictions on use of collections. Often they appear without notice and with only minimal knowledge of a repository's holdings. They may balk and call having their notes screened "censorship," and they may neglect to furnish the repository with copies of their publications. Nonetheless, it is the archivist's responsibility to impress upon the researcher the legal and ethical implications of the material he is using. If the archivist makes it clear that his concern for confidentiality is not merely *pro forma* and demonstrates a willingness to allocate his own time to enforcement of standards, the researcher is more likely to be convinced of the seriousness of the obligation.

The acquisition and administration of health and welfare case records pose complex issues for the archivist. Such collections are, nonetheless, worth obtaining for their wealth of data and significant research possibilities. Dealing with case records offers a professional challenge to the archivist. The archivist must seek out case records that are now being routinely destroyed, make final judgments about their value for permanent retention, and convince their compilers of the appropriateness of archival deposit. The problem of volume of records becomes critical in making these appraisals. Furthermore, the growing computerization of records systems demands a new level of expertise for the archivist.²⁰ Present trends toward machine-readable data systems in health and welfare institutions will accelerate in the future, producing more data and more methods of linking disparate systems of data. If these records are to come under archival control, the archivist must become familiar with the format of computer-accessible information.

Computerization of records presents a new dimension to the questions of personal privacy versus social utility. The control mechanisms over hardware and software are currently more honored "in the breach than the observance." In addition to the technical problems of maintaining system security, there exists a problem peculiar to computerized systems:

²⁰ For discussion of a multistate system of psychiatric records and information, computer-based, see William J. Curran et al., "Protection of Privacy and Confidentiality," *Science* 182(1973):797-802.

... one of the potentially most significant effects of computerization on personal-data record keeping is the enhanced ability to gather, package, and deliver information from one organization to another in circumstances where lines of authority and responsibility are overlapping or ambiguous and where the significance attached to data disseminated by the system may vary among subscribing organizations.²¹

The emphasis in this situation is on the need for custodians of information to assume responsibility for the uses to which that information is put. Whether the data is recorded on typed pages in files or by magnetic impressions on tape, the problems of privacy are conceptually the same. Someone must delineate policy on access to and acceptable use of data which exists in record systems.

Policy formulation is the most difficult and most important task for the archivist who controls records with vast potential impact on individual lives. The archivist has the immediate responsibility for maintaining rigorous standards in the protection of personal privacy on behalf of persons who may be unable to assert their rights—because they are legally incompetent to do so (children, institutionalized persons) or because they are unaware that records involving them have been transferred to an archives. Professional ethics far beyond the vaguely formulated archivist's code are demanded to meet this responsibility.

Finally, because the legal status of case records is subject to widely differing interpretations in the states, there exists a real opportunity for archivists to participate in the development of statutory and case law relevant to their holdings. The archivist must assert the historical value of data contained in case records and assist in balancing the competing norms of privacy and information flow. Since the legal concept of privacy is in flux, the archivist should contribute to the definition and implementation of realistic records practices. These issues transcend local jurisdictions and should engage the attention of the profession in setting national standards. Preservation of these resources demands an activist stance.

²¹ U.S., Department of Health, Education, and Welfare, *Records, Computers and the Rights of Citizens: Report of the Secretary's Advisory Committee on Automated Personal Data Systems*, Dept. HEW Pub. No. (OS) 73-94 (July 1973), p. 19.