PRIVACY AND PATIENT RIGHTS

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To understand the dramatic change that has occurred in medical record-keeping in the last several decades one must appreciate the role of such records in contemporary society contrasted to their role of many decades ago. In the early part of the century, health records tended to be a local matter; the individual physician maintained, perhaps in a card file, the dates at which a patient visited him, the drugs he prescribed and the financial status of the account. Insurance was not a widespread social phenomenon, and to the extent that health information played a role in insurance eligibility decisions, the insurer would collect what he needed directly from the applicant and supplement it with a company-sponsored physical examination or verification of the facts. Thus medical recordkeeping was largely a private affair between the individual and the one or few health care providers with whom he interacted.

Today, however, the situation is dramatically changed and for many reasons. Health care technology per se has advanced unbelievably; the scope of medical treatment now available and specialization of those who provide it has increased almost without limit. In view of such progress, it follows that use of health care inevitably would escalate not only because of simple growth in population but also because the individual's consumption increases simply due to its availability. Furthermore, the health care professional now tends to specialize in a relatively narrow part of the spectrum of health technology. Thus, in treating complex cases -- or even simple ones -- many such professionals need to communicate with one another at remote distances and different times; the health care record has itself become an important tool in the very delivery of the service which the record documents. To put the matter in

perspective it is estimated that in 1975 Americans visited a physician 1.56 billion times, an average of slightly over five for each person in the country. Each such contact, of course, creates a new medical record or enlarges an existing one; but it is revealing to note that of the total content in medical records, it is estimated that only approximately 1/3 will have been entered by physicians. Because of increased longevity medical records tend to be kept for decades, and thus the sheer volume of information contained in (say) 50 years of medical records is staggering.

Quite aside from the role of medical records in delivery of health care is their collateral use in many important roles for society. Among them are the following.

- o Employment Health information is routinely sought for most job placements. For certain critical jobs, detailed long term health records can be essential. In some cases an examination of an individual's health status is even mandated by law, e.g., for food workers. In other instances even psychiatric information will be required, e.g., an examination of suicidal tendencies in applicants for a bus driver.
- o Insurance Decisions Most purchases of life insurance involve revelation by the applicant of certain health facts about himself; for unusually large policies a detailed health exploration can be required. Less obvious, however, to the individual is the role of health-record information in other insurance processes, such as adjudication of claims, prosecution of malpractice suits or conduct of epidemiological research.
- o Third Party Payers Private health-insurance coverage now includes almost 90 percent of hospital expenses and 60 percent

of physician services as opposed to approximately 1/3 of personal health expenses just 25 years ago. Furthermore, in view of government programs to fund health costs for the aged and disabled, tax revenues also cover a large share of the national health care bill. The settlement of each claim under an insurance program involves access to the health record in question, and therefore an enormous traffic in such records for this purpose has developed.

- o Government Mandated Records Vital statistics have long been accepted as a part of health information required by government. In addition, however, there is also now compulsory reporting to the National Center for Disease Control Prevention and to the National Center for Health Statistics. The job related records required by the Occupational Safety and Health Act and the information required to support Professional Standards Review Organization are other examples. For each of these -- and other -- purposes, health information about individuals is required by law.
- o A General Source of Information About People In this dimension, health records have become useful to the enforcement mechanisms of various organizations -- law, drug, alcoholic abuse -- and even play a role in the public's assessment of its political candidates.

To put the point in perspective, a 1970 survey of California psychiatrists indicates that 89 percent of them had been asked for medical record information by insurance companies, 56 percent of them by schools and 49 percent

by employers. Furthermore, a photocopying firm indicates that it photostats some 365,000 medical records per year for a State disability insurance program. It is estimated that roughly 10 percent of requests for medical records are in the form of subpoenas.

A second important change in health recordkeeping is the voluminous nature of each one. No longer is it a simple hand-kept record on a card, but now sheet after sheet of data -- sometimes computer printed, sometimes hand entered, sometimes from automated equipment -- that comprehensively describes an individual's progress through all the years of his interaction with the health-care community. The record has become an even more complete characterization of one's health because of the enormous scope of health care available and because also of the automation of some of its processes. It is in fact less expensive for the patient to have certain laboratory tests done as a battery by automated techniques than to do only the one or two that the physician wishes. Thus, the very progress of health care technology itself tends to enlarge the dossier-like nature of a contemporary health record.

Yet a third aspect of modern health recordkeeping is the ease with which records migrate from organization to organization. It is driven largely by the enormously expanded role of health records in contemporary society, but also by the demand of government agencies for access to such information in monitoring of programs, monitoring of health care delivery, support of research, auditing of federally funded programs, etc. The health care record has become an item of commerce that is traded -- or sometimes sold -- among organizations with minimal concern for the impact on the individual involved.

Yet another characteristic of modern day health recordkeeping is the broad authority that certain organizations have to solicit such information.

The applicant for life insurance or certain other liability insurance is well familiar with the broad and comprehensive authorization statement that he is obliged to sign in order to do business with an insurance company. The net effect of such "voluntary" authorizations is that many of society's institutions have sweeping permission from an individual to dragnet the health-care community for information about him.

> A recent major study* summarizes the situation in this way: "... the outward flow of medical data has enormous impact on people's lives. It affects decisions on whether they are hired; whether they can secure business licenses and life insurance; whether they are permitted to drive cars; whether they are placed under police surveillance or labeled a security risk; or even whether they can get nominated for or elected to political office."

Because of traditional practices in the institutions of health-care delivery, medical records tend to be shared freely upon request of any inquiring party. Thus from a privacy point of view, confidentiality of medical record information has clearly been seriously eroded and the patient has little control over how his records are used, circulated or even exploited. The dilemna is compounded by a recent California statute stipulating that hospital records are its property. Such a position indicates that a health care record is to be treated as tangible property, and therefore is largely under the sole control of its owner to be used as he sees fit. Yet is clear that many personal facts in such a record -- name, address, age, birthdate -- are

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*Computers, Health Records, and Citizen's Rights, Alan F. Westin, United States Department of Commerce, Washington D.C. 1976, p. 60.

still the property of the individual in the sense that he is free to use them elsewhere as he chooses. In effect, a patient in a California hospital is obligated to relinquish control over information about himself as a condition of receiving health care from that institution. It is clear that ownership is a complex and intricate issue; when it concerns personal information, it is not at all obvious that treating it as tangible property is an appropriate approach. Until -- or if -- the ownership issue is resolved, control by the individual over the use of information about himself is the only practical approach.

Thus, medical records in today's world are significantly different in character and play a dramatically broader role in society than did medical records a few decades ago. The computer is -- as it is in so many other areas -- a driver of the problem rather than the fundamental source of it. With a modern computer's capability to store, retrieve, correlate and distribute information, medical recordkeeping has become a body of voluminous, comprehensive records used widely for many purposes. As the computer so often does, it has moved a long-standing chronic problem that society could tolerate into an acute one of great concern; it causes such an effect simply by making comprehensive information available on a timely basis to a wide scope of users for broad and diverse purposes.

In such a situation what are the expectations of the individual about whom a medical record is kept?

- He expects to be treated fairly by the record system in the sense that the record per se will not be the source of an unfair decision about him.
- He expects accuracy in the recordkeeping system lest wrong entries expose him to harmful, inappropriate, dangerous or

unnecessary medical treatment. Thus, he has an inherent interest in assuring accuracy and completeness of the record by having a right to see it and to cause corrections as necessary.

- o He expects openness from the recordkeeping system in the sense that he knows what information will be used for, with whom it will be shared, for what purpose it will be shared and how it will be verified. He wishes to participate in the control of information used for purposes other than for which it was originally collected.
- o He expects that records maintained about him will be treated as confidential. While he has willingly provided information about himself in exchange for medical treatment, he does not expect such information to be used beyond the purposes of such health care delivery, plus such supplementary ones as are mandated by law or generally accepted by society. In particular, he does not expect information about himself to be given without challenge to third parties, especially to enforcement agencies, tax authorities, or other government agencies. He needs the protection of a judicial review process in such circumstances.
- o He expects to be protected against intrusive collection of information. An organization soliciting information from him should collect what is needed for the purpose but no more, by open straightforward methods without pretext or subterfuge.

The many dimensions noted above collectively characterize current concern over <u>personal privacy</u> in the context of recordkeeping systems.

To put it another way, an individual expects a recordkeeping system to fully inform him about its operation, collection and use of information; he expects such information to be made available by such a system only to authorized users who have a need-to-know for it in the course of duties pursuant to the reason for which the information was originally given; he expects such information to be complete, timely, accurate and protected against casual access by non-authorized persons. When a circumstance arises in which the good of society may transcend that of the individual, he expects an appropriate legal process will be invoked to adjudicate that confrontation.

Against the background of present concern for the privacy of individuals, what do we find the situation to be? Because of institutional traditions and historic relationships among institutions, control of medical records today tends to be minimal. In the gradual transition from a card index kept in a physician's office to the voluminous records of the contemporary hospital record room, insufficient thought has been given to the physical protection of such records, to procedures for assuring their accuracy, or to controls that assure access only by authorized personnel. As with most recordkeeping institutions, hospitals have tended to accept the view that any request for information about an individual is legitimate and should be honored; the management attitude is often one of casualness toward the whole matter. Thus, informal arrangements for sharing information between the medical community and outside organizations have gradually evolved. While such channels cater to the special interest of one or a community of organizations (e.g., insurance) they may not be in the best interest of the individual and certainly they are invisible to him and outside his control. Thus the recordkeeping scene in the contemporary hospital is not one that well serves the privacy concerns in today's society.

Over the past two years the Privacy Protection Study Commission* has examined a large number of recordkeeping areas, including that of medical care. Its final position is generally that outlined above in terms of individual expectations, but for each area it has proposed a series of recommendations to remedy recordkeeping deficiencies and abuses that have been identified through public testimony and staff studies. Its final report** includes a series of four general recommendations and ten specific ones for the medical-care relationship. The latter relate to such things as:

- o the patient's right to access, see and copy his records
- o the patient's right to correct or amend a record found in error
- o performance standards for recordkeeping systems to protect and control access to their records
- o establishment of a legally enforceable expectation of confidentiality for medical records
- o control of third party disclosure whereby just that part of the record necessary for the purpose of the request would be disclosed
- o a requirement that a disclosure made without an individual's authorization must be reported to him
- o a requirement that individually signed authorizations for release of information must be specific in all details, and

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*Created by the Privacy Act of 1974, P.L. 93-579.

**Personal Privacy in an Information Society -- the Report of the Privacy Protection Study Commission, July 1977, U.S. Government Printing Office, Washington, D.C. 20402, Stock No. 052-003-00395-3.

- o a requirement that release of information pursuant to an authorization is noted in the record from which the disclosure was made.

The four general recommendations provide for implementing the specific ones by several mechanisms. In a case of medical care providers reimbursed under titles XVIII and XIX of the Social Security Act, the Act would be amended to require that such providers show evidence of compliance with the specific recommendations. Furthermore, each state would be asked to create a statute establishing the individual right of access and correction, and an enforceable expectation of confidentiality. For health care providers not within reach of federal or state actions, it is urged that compliance be on a voluntary basis. Finally, it is recommended that federal and state penal codes be amended to make it a criminal offense to request or obtain medical record information under false pretense or through deception.

If the position of the Commission is accepted and its recommendations -- or some approximation to them -- are implemented in law, then hospitals will find themselves faced with having to respond. For a hospital that already has a well protected and well controlled record system that is responsive to contemporary societal and individual concerns, the impact will be nominal. For the hospital whose recordkeeping function is based on bygone practices and procedures, or whose record system is casual, slipshod or inadequately controls access to and flow of record information, the impact will be substantial. A hospital unavoidably will have to view the health record as a commodity equally as valuable as an operating room, a narcotic drug, a whole body scanner -- and will have to protect and control it accordingly. Health records will have to be made physically safe; access to them will have to be

limited only to authorized individuals for authorized purposes; positive management affirmative actions will have to be taken to enforce new rules and regulations and to institute penalties for infractions. Information in general -- and the medical record in particular -- will have to be viewed as an asset of the hospital that has high intrinsic value to government agencies as well as commercially, and will be subject to a variety of threats that in one way or another can subvert the use for which it was originally created.