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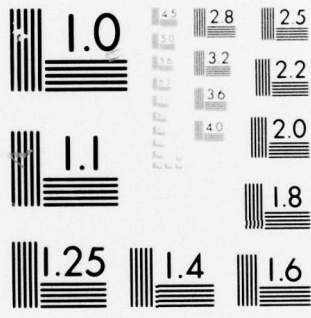
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FEDERAL AND STATE REGULATIONS CONCERNING THE
PRIVACY OF HEALTH CARE DATA *

While my topic concerns federal and state regulations concerning the privacy of health care data, I want to take license with it and speak to the intent rather than the letter of the title. To give some overview to the subject, the American Hospital Association testified before the Privacy Protection Study Commission that in 1974 some 7,100 of its members created records on roughly 35 million inpatient admissions, 71 million emergency room visits, and 108 million clinic visits. That represents something over 200 million hospital visits and therefore hospital records, approximately one visit for each person in the country. It gives a sense of the magnitude of the health care business; the numbers are large. As large as they are, they are only a small part of a much bigger demand that is growing for information as we, a large country with a large population, lead increasingly complex lives and surround ourselves by increasingly large government programs, all of which have to be accountable.

The first order of business is to define terms. Confidentiality, privacy and security are three words with close links, but with somewhat different meanings. Confidentiality is a status that is accorded to data indicating that for some reason it is sensitive and needs special protection. By implication, there is control over dissemination; were it to be freely available to anyone, then obviously it could not have special status. Arguing in reverse, it follows that the special status of confidentiality implies control of dissemination, and control of use. Sometimes the control is assured by law but frequently not.

Privacy is the social expectation that an individual will have some control over the use of information about himself. It is the social expectation that decisions made about an individual and involving records will be fair ones. Finally it is the social expectation that the individual will be protected against excessive or obtrusive collection.

* A talk presented at a symposium sponsored by the University of California, Los Angeles on November 5, 1976.

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Security is the set of safeguards put into a record-keeping system that accomplishes three things. First, the safeguards protect the system per se, its equipment if computerized, its data, its people, and its facilities against damage from some threat. Secondly, the safeguards assure the owner of the system that it will not be denied to him. One does not want dissident groups capturing essential data systems that support important societal functions. Finally, security safeguards assure that information is divulged only to authorized recipients. By implication, the safeguards assure that it is not divulged to unauthorized recipients.

The real subject for discussion is not privacy of health care records, but rather the confidentiality of the health care records with an overlay of privacy as it relates to emerging social expectations. There are several parts to the matter, so first I will give a quick summary of affairs at the state level. The source of my information is an appendix from a January 1973 report of the Secretary's Commission on Medical Malpractice. A January 1973 date implies that it is 1972 data; therefore, it is roughly four years old, but I think that the general pattern and the general picture will be correct. In general, State regulations or state laws are frequently completely silent on rights of access or legal status of records; nothing is said. Secondly, the question of ownership of the records is almost never discussed; the California law in regard to hospital records is a rare event. Third, whatever coverage there is in whichever states have it, is very uneven in its completeness and is quite variable. Sometimes the coverage applies only to public institutions and sometimes it applies as well to private institutions. The data indicates that of the 50 states, plus the District of Columbia, 37 are absolutely silent on aspects of protection or access to health care records. There are 9 that provide some kind of regulation through boards of health or corresponding entities; there are 3 that provide some kind of regulations through hospital organizations. There are only 2 that have some legal status established, one of them by common law and one through its established rules of procedure.

To summarize in another dimension, 37 are silent on subject access to the records, although other access may be covered. Of the 14 that

have some provision for subject access, 9 provide access by explicit law and one by case law. When there is subject access, sometimes it is only through his treating physician as a channel; sometimes it is through his treating physician's consent; sometimes the subject gets the record only after discharge from the hospital; sometimes the subject is given direct property rights in law and in one instance, the subject has legal, undeniable right and interest in law but he may have to go to the courts to exercise that right. It is very variable across the states.

With respect to access to health records by a subject's attorney, 43 of the states are absolutely silent; 8 have some provision, 6 by law and one by regulation; one, simply because it grew up as a practice. Sometimes in those that try to control it, patient consent is required, frequently not. With regard to access by third parties other than a patient's attorney, 18 states say nothing, and 33 have some provision. Sometimes provision may be a court order or a subpoena; sometimes access by a third party may require the consent of the hospital or of the physician or of the patient or some combination of them; sometimes access is given to insurance companies and sometimes to law enforcement agencies and sometimes to boards of health and sometimes to "any interested persons" with a legitimate interest. Sometimes access is to a patient representative; sometimes, to any authorized hospital personnel; sometimes, to "government agencies"; sometimes, to licensing agencies. The matter is extremely variable. Only in very rare instances is anything said about the confidential status of health care records at the state level; in such instances, patient consent is required for access.

The word "confidential" just does not arise except in very few states, but the fact that at least some of the states attempt to impose access controls implies that confidentiality is intended although not stated as such. Do keep in mind that 37 states say nothing about the whole subject.

Mental health records get special treatment in most states, but of the 51 governmental entities, 27 are silent on mental health records; 24 make some provision, 5 states explicitly. Five of the 24 explicitly define mental health records as confidential. In other cases, access may require consent of the patient; it may require a court order; access can be available to boards of trustees of institutions, to attorneys, or to

physicians. Sometimes access is at the discretion of the management of the facility. In a few states, access is explicitly prohibited without patient consent or without court order. Since there is some attempt by the state to limit access, by inference there is an implied status of confidentiality.

From a different point of view, information maintained by state-administered or state-supported hospitals is of special concern because such facilities may find themselves under the cognizance of one of the so-called "sunshine acts." A Freedom of Information Act, or a Public Records Act seeks to make the records of all public institutions publicly available. From this perspective and using again the same source of data, 15 of the states specifically exempt health care records from whatever act each might have that gives public access. Five others exempt records only if otherwise confidential; so it takes a second law to establish a health care record as confidential if in one of the 5 states it is to be exempted from public access. It so happens that all five have a physician-patient privilege statute that presumably would establish a confidentiality requirement. Some states exempt only certain aspects of health care records from public access. Slightly over half of the states say absolutely nothing about the matter and presumably any legal test in one of them would get health information into public view.

Whatever arrangements happen to exist, terminology is widely variable; it is quite uncertain just what record content is protected. Sometimes a law or a regulation speaks of hospital records; sometimes, clinical records; sometimes, medical records; sometimes, medical, psychological or sociological data; sometimes, public hospital records; sometimes, vital records. Sometimes, a law or regulation refers to people receiving public medical assistance; sometimes, to identity of people required to report for public health reasons. Sometimes, there are exemptions to the otherwise existing controls, for example the records of a deceased person. Other times, the exemption from access-control references a criminal act or an insurance-compensatable event. Overall, there is much health care information available for public inspection and with essentially no control over access to it--it is there for the taking. The state scene on the whole is widely variable, and it is not always clear just what the

circumstance would be without a legal test.

With regard to the final aspect of the situation, 43 states have some physician-patient privilege laws, but in 6 of the 43, that privilege is limited to psychiatric records. Generally such statutes apply to any institution; and therefore, such physician-patient privilege laws would presumably protect, at least in part, access to records in hospitals. However, the details are widely variable; there is no way to summarize it in an orderly way. It amounts to a potpourri of laws, regulations and case law.

At the federal level, the situation is quite different. While there is a federal Freedom-of-Information Act, it has a number of exemptions-- health records is one of them. Under the federal FOIA, health records are not available except to the data subject or the patient himself. Drug abuse and alcoholism information receive special treatment because the legislation that created these national efforts specifically provides that it will be treated as confidential, although the authority for establishing the protected status of confidentiality is not absolute and written into law, but rather is given to the Secretary of Health, Education, and Welfare. Whatever rules he chooses to establish governs how drug abuse and alcoholism information is used and protected. In the case of the National Center for Health Statistics, the law prescribes the permissible uses of the data collected, prohibits other use, specifies how it shall be published, and establishes immunity from judicial seizure. There is an option for the Secretary (DHEW) to establish new uses under his authority, but none have been. It is interesting to note that in the special two categories noted, whatever protection the health information has results from the formal rule making process of the federal government in contrast to the situation for census data for which the law specifies that the data will be confidential and speaks to its protection. Because of the variability of the language and the structural details of the various laws, it is hard to say what the precise bounds of confidentiality are, even for the three special classes of information. It is hard to say in a general way what permissions are required to access it.

Finally, there is the now well-known Privacy Act of 1974 at the federal level. There is no easy way to give a summary of its consequences

because much of the action is still playing out. The Act has been in operation for only a year; not all of its consequences are yet visible. In a broad way, that Act requires Federal agencies to publish an annual notice that describes all record systems, states what the subject matter in each system is and how it is used, describes the data sources, etc. The Act gives each of us as individuals in this country, rights to inspect records, to contest them, and to cause them to be corrected if found in error. As part of the public notice, each record system is required to describe what is called "routine use"--an effort to detail and control the way that information can be used. In part it reflects an effort to give back to the individual some control over the use of information about him. One can buy from the Office of Federal Register a "telephone book" that lists some 8,000 record systems of the federal government. In it one can find health care--or other--record systems that might be of interest, go to such agencies and ask to see records that each might have about him. In this sense there is parallelism between the Freedom-of-Information Act and the Privacy Act; each gives the subject access to medical records, but it so happens that the Privacy Act works more smoothly, and provides more direct access.

A very significant aspect of the Act is the creation of a national forum in which privacy matters are being investigated in a very broad way. During the Congressional debate that led to the Act, one view held that it should apply to all record systems in the country but another held that it should apply only to those of Federal government. In working out the conflict, a part of the compromise position was to create a Privacy Protection Study Commission to examine the part of the problem that had been temporarily deferred.

The tasks before the Commission are lengthy, but the item of interest for this discussion is that of medical records or health records--obviously a sensitive area. The Commission is looking at the whole situation from both the public and the private sector point of view. It has held a series of hearings, some of them in Los Angeles and some in Washington, to establish an understanding of record-keeping processes for health care records in public and private institutions. Quite aside from the use of such records for patient care, the Commission has

developed insights into the use of the records by such diverse groups as consumer reporting companies, employers, credit grantors, insurance companies, third party payors, and even educational institutions. Many uses are for purposes quite tangential to the reason for originally creating the health record. There is substantial testimony indicating that confidentiality, when and where and if it happens to exist, has been subverted in surprising ways. The most startling one that has come to light is the so-called Factual Services case in which a company specialized in acquiring medical records from hospitals and other sources for insurance claim settlements. The company engaged in such questionable tactics as sending an employee to a hospital dressed as a physician or as a clergy to seek information and/or "acquire" a record. Alternatively, an employee would phone a hospital at off hours and posing as a physician, would seek and obtain information about some individual. The situation has been documented widely in public records and the press; legal action is now pending.

On the basis of such happenings, and on the basis of what I have observed personally from hospital visits, I am convinced that hospitals will have to establish much better controls over access to records. Hospitals will have to make a self-assessment of the threat against the health care records and then will have to take conscious steps to create safeguards to counter whatever threat is perceived to exist; hospitals will have to assure that health records are available only to authorized users. Hospitals will have to take affirmative steps to train personnel and to focus management attention on an area of increasing importance. Why? Medical records as a source of information about people have suddenly been discovered as very important to a whole host of collateral questions that have nothing to do with health care, but rather have to do with settlement of insurance claims, getting a job, granting credit, or some other thing. There is an interesting anomaly to the whole story. Somewhere out on the edge of the whole thing is the patient and the question of his access to health records. It would almost seem that he is the only person who cannot get them. That would appear to be especially true given the very broad and general consent form that is at the bottom of every insurance application.

As a Commission we have very difficult and complex issues to face with regard to health records. Among them are: Should the patient have access to records? Should this access include the ability to correct a record if the patient believes it is wrong or can demonstrate that it is wrong? Should there be some absolute right of access if a patient record is disclosed to a third party, as opposed to being used for health care? What procedure should be used to prevent authorized disclosure of medical record information: What rules should apply to the researcher's access to medical records? What problems are likely to arise under a system of medical health insurance? The issues are tough ones, in part because in the last 10 years or so, an individual's medical record has become an important document, both to himself and to the entire community of record systems with which he must interact. While there are health professionals who believe for good reason that the individual should not have access to his records, there are arguments on the other side as well. The issue will be very difficult to adjudicate.

While we have a lot to do, the Commission deadline is June 1977. Our goal with respect to health records is to document what the practices are in health care record-keeping, and what the information is used for and how; and second, to report to Congress and to the President recommendations that will assure adherence to fair information practices among health care providers and institutions, and other parties that use such records. As a Commission, we are attentive to the view that it is neither desirable nor feasible to extend the broad principles of the Federal privacy act to the public and private institutions that provide health care. On the other hand, we must weigh both sides of the case and come to our own decision. We will have to reach our own judgements of feasibility and costs; we have to determine whether legislation is even needed--and if so, what kind. It is clear that confidentiality safeguards can be breached if someone wants to badly enough. Based on what we have heard, we are inclined toward the view at the moment that it is essential there be a national policy that governs the circulation and use of health record information. Moreover, given the broad usage that health care information has acquired, it also appears to us that the subject of a health record should have some form of access to it. Perhaps the access should include

an intervening physician; perhaps it should be direct when circumstances warrant. Whatever the means, how and when should the data subject have some right to access to his health information?

It is clear that the issues posed by the record-keeping practices of health care providers will not be easy ones to solve. It is clear that it is very easy to have ideas about how to tighten things, but also it is clear that it is very easy to have an idea with serious consequences in terms of closing information sources to people who really ought to have it, in terms of imposing unnecessary costs on record-keeping practices or in terms of making record-keeping practices very awkward to conduct. As a Commission, we are alert to the several aspects and it is our expectation that the final recommendations will satisfactorily address the delicate confrontation of how to protect individuals against the use of information about them in unauthorized or damaging ways vs. how to assure that health care information is made available as needed for socially acceptable purposes.