

Medical Privacy and the National Health Information Network Initiative

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INTRODUCTION

Traditionally, medical data were typically collected and stored as records in physicians' offices and hospitals. Often the data were recorded manually and retrieved manually. Today collection and retrieval of medical data are increasingly done using information technology (IT). The introduction of IT, especially e-technologies, has changed the handling of medical data in ways that are both promising for improving health care as well as threatening to the individual patient's medical privacy.

This chapter will examine medical privacy and the National Health Information Network (Kaushal et al., 2005) initiative. Other technologies such as radio frequency identification device (RFID), voice over IP (VOIP), and telemedicine, while relevant to the topic of medical privacy and IT, are tangential to the more central issues of electronic health records, medical databases, and the development of a national health information network. Although the focus will be on medical privacy in the United States, it is evident that people in other countries are also concerned about their medical privacy. Singaporeans, especially Malays, worry that their medical histories may result in racial discrimination. In the area of medical research, the Chinese and Indians want their medical information confined only to the area of study that was originally agreed to and not disseminated widely (Tan, 2006).

THE MEDICAL RECORD

Patient data form the *medical record* and its contents (www.eff.org/Privacy/Medical/1993_ota_medical_privacy.report).

Medical records may contain patient data such as name, address, age, next of kin, names of parents, date and place of birth, marital status, religion, history of military service, Social Security number, name of insurer, complaints and diagnoses, medical his-

tory, family history, previous and current treatments, an inventory of the condition of each body system, medications taken now and in the past, use of alcohol and tobacco, diagnostic tests administered, findings, reactions, and incidents. Records may also contain subjective information based on impressions and assessments by health care workers such as mental ability and psychological stability and status. In addition to data about the patient's current condition, the medical record may also contain the results of genetic research and testing that enable predictions of future medical conditions and the prospects of developing specific medical problems.

Traditionally, the creation and maintenance of medical records were done manually by health professionals, mostly as an aid to memory. But IT is changing this practice. Notes handwritten by doctors and nurses are being put into electronic form in the name of faster, more extensive access to needed information. Healthcon and other health care companies are competing to get doctors to write prescriptions over the Internet and to persuade people to place their personal health records on the Internet (Consumer Reports, 2000). Companies have made software available that an individual can use to create an Internet-based personal health record that can be used to organize family medical histories, including medical conditions, medications, and allergies. These personal records may be transmitted to health professionals over a computer network (Rubenstein, 2005).

Medical records are available online to medical practitioners for the purposes of decision-making and improving health care. They are also available to other users and institutions in nontreatment contexts. Medical records are used to conduct federal government-mandated medical community audits of physician competency and performance. They are also used by insurance companies in the assessment of an applicant's eligibility for health and life insurance and in claims processing to detect medical fraud. Medical information is also used by private employers, educational

institutions, credit investigators, and law enforcement agencies for a variety of nonmedical reasons.

THE IMPORTANCE OF MEDICAL PRIVACY

Cate (1997) identified a number of conceptions of what constitutes privacy from the literature. Privacy has been viewed as an expression of one's personality or personhood, focusing on the right of the individual to define his or her essence as a human being; as autonomy—the moral freedom of the individual to engage in his or her own thoughts, actions, and decisions; as citizens' abilities to regulate information about themselves and thus control their relationships with other human beings; and as secrecy, anonymity, and solitude.

In the area of medical information, the definition of *privacy*—"the claim of individuals, groups, or institutions to determine for themselves when, how, and to what extent information about them is communicated to others" (Westin, 1967, p. 7)—is consistent with the confidential relationship between doctor and patient. Confidentiality refers to how data collected for approved purposes will be maintained and used by the individual, group, or institution that collected it, what further uses will be made of them, and when individuals will be required to consent to such uses. Privacy may be construed as a balance struck by society between an individual's right to keep information confidential and the societal benefit derived from sharing the information and how the balance is codified into legislation, giving individuals the means to control personal information (Office of Technology Assessment, 1993).

Various public opinion polls conducted since 1993 have uncovered a basic concern people have about the privacy of their medical records and how these records may be used (www.epic.org/privacy/medical/polls.html). Among the major concerns of those polled are the following:

- Personal health insurance information might be used by employers to limit job opportunities.
- Sensitive health information might leak because of weak data security.
- Protecting the confidentiality of medical records is absolutely essential or very important in health care reform.

- Existing federal health privacy rules protecting patient information may be reduced in the name of efficiency.
- The trend of the health care system to keep medical records electronically raises threats to their privacy.
- Medical records are more secure on paper than in electronic form.
- Medical and government researchers should not be allowed to study an individual's genetic information unless they first obtain his or her consent.
- Government agencies, insurance companies, and researchers are allowed to see medical records without the patient's permission.
- The federal government is requiring everyone to be assigned a medical identification number, similar to a Social Security number, to create a national medical database.
- Insurance companies are getting more information from patients' doctors than is needed.
- Medical information from a computerized national health information system will be used for many nonhealth purposes.
- It is important that individuals have the legal right to obtain a copy of their own medical record.

Federal and state governments have attempted to deal with these issues in ways that satisfy the needs of various stakeholders, such as doctors, dentists, chiropractors, insurance companies, researchers, law enforcement, and data processing firms, as well as individuals. The result has been various legislative measures that provide legal compromise for the stakeholders.

MEDICAL PRIVACY LEGISLATION

It should be noted that the Bill of Rights does not address privacy issues at all. However, in *Griswold v. Connecticut* (381 U.S. 479 (1965)), the Supreme Court found sources for a right to privacy in the First, Third, Fourth, Fifth, and Ninth Amendments to the Constitution of the United States in the form of "zones" or "penumbras" of privacy (www.eff.org/Privacy/Medical/1993_ota_medical_privacy.report). A major modern discussion of an information privacy right is *Whalen v. Roe* (429 U.S. 589 (1977)), wherein the Supreme Court accepted that a right of privacy includes a generalized "right to be let alone," which includes "the individual



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