

LIFT PERSPECTIVE

A publication of the Texas Conservative Coalition Research Institute
January 21, 2000
Vol. 1 No. 2

The Invasion of Medical Privacy

The Health Insurance Portability and Accountability Act of 1996 (HIPPA) required that the Secretary of Health and Human Services (HHS) promulgate regulations concerning privacy standards of electronic medical records if Congress failed to pass legislation establishing such standards by August 21, 1999. The deadline passed without the required legislation, and proposed rules have been posted for comments in the *Federal Register*. Those proposed rules have brought the issue of the privacy of medical records to the forefront of public policy debate.

Invasion of Privacy #1. Concerns over the abuse of medical privacy made headlines in 1997 when the Texas Legislature passed a bill approving the creation of a statewide immunization tracking registry (ImmTrac). Initially filed with the intent of collecting immunization information on every child in the state without parental consent, heavy opposition to such a practice resulted in

amendments to the legislation requiring a parent's permission to collect or use the information. When proposed rules by the Texas Department of Health (TDH) to implement the legislation were made public, parents were dismayed that the informed consent section was not included in the rules. Their concerns about the potential for the inappropriate use of their children's information were validated when it became known that 3.3 million names of children were dumped into the registry from the Texas Bureau of Vital Statistics data. Some of those children had received immunizations from public providers, and therefore, their names could legitimately be entered into the database. However, over 700,000 names of children who had been treated by private providers were illegally entered into the registry without parental consent.

Ironically, the parent leading the opposition to the registry discovered that her child was one of those whose name had been illegally entered. The child had been assigned an Immunization Tracking ID number, and the parents' Social Security numbers were included in the registry. The TDH then affirmed her fear that information could be released to unauthorized requestors by faxing

Key Issues:

- Medical records are private and access to them should be controlled by a contract between the patient and the provider and/or payer.
- Fear over the unauthorized release of records undermines the doctor-patient relationship and can interfere with medical treatment.
- The compilation of or access to personal medical records by the government is inappropriate because of the coercive power of the state to misuse the information and thereby abuse the privacy and liberty of the citizen.

a copy of her daughter's immunization history without seeking verification of her identity.

Though the final version of the TDH rules addressed many of the concerns of parents and complied with the legislation, TDH has since called a meeting of all stakeholders to discuss the "burden" that informed consent has created.

Invasion of Privacy #2. *HCFA's Latest Assault On Patient Privacy*,¹ a report published by the Heritage Foundation in Washington, D.C., indicates that the issue of medical privacy and the collection of personal information is a federal as well as a state issue. That report disclosed that the Health Care Financing Administration (HCFA), the agency charged with running the Medicaid program, has proposed rules to force home health care agencies (HHAs) to collect and report personal information on their patients without the knowledge of the patient.

The data collection would not be limited to Medicaid patients (who arguably may have forfeited some privacy rights when they chose to accept government money) and would cover patient history and demographics, as well as financial, behavioral and psychological profiles. Specifically, HHAs would be required to report whether the patient had expressed "depressive feelings," a "sense of failure," "had thoughts of suicide," had used "excessive profanity" or made "sexual references."²

Invasion of Privacy #3. The immediate battle being waged at the national level is over the HHS promulgation of regulations concerning privacy standards of electronic medical records. Those rules include the use of a unique "health identifier."

First proposed in the 1993 battle to reform health care, legislative requirement for the creation of a unique health identifier was not in place until the passage of HIPPA in 1996. That legislation required HHS to assign an identifier to each individual, provider, health plan and employer. This identifier would be used to compile a complete medical history on every individual and could be transmitted to a central database or clearinghouse.

For now, Congress has placed a temporary moratorium on federal spending for unique health identifiers, but it has not repealed the section of code requiring the creation of them. According to an article by the Institute for Health Freedom, "the HHS is considering six alternatives for creating unique health identifiers, including biometric identifiers that employ DNA analysis or voice recognition technology."³ As long as the health identifier remains viable, creation of a central electronic medical database remains probable. Creation of the database coupled with the loss of control of an individual over his personal medical records constitutes a massive governmental intrusion into personal liberty and privacy.

Congressman Ron Paul eloquently summed up the concerns of collection and abuse of records by the government in his comments on the proposed rules concerning medical privacy regulations made to the HHS:

These regulations violate the fundamental principles of a free society by placing the perceived "societal" need to advance medical research over the individuals right to privacy. They also violate the Fourth and Fifth Amendments by allowing law enforcement officials and government-favored special interests

¹ Robert E. Moffit, Ph.D, Executive Memorandum 580: *HCFA's Latest Assault On Patient Privacy*; Heritage Foundation, March 22, 1999.

² Ibid.

³ Institute for Health Freedom, "What Americans Need To Know About Medical Privacy Regulations," <http://www.forhealthfreedom.org/Publications/Privacy/NeedToKnow.html>, January 11, 2000.

to seize medical records without an individual's consent or warrant and could facilitate the creation of a federal database containing the health care data of every American citizen. These developments could undermine the doctor-patient relationship and thus worsen the health care of millions of Americans.⁴

Private-Sector Abuses. Though not as potentially dangerous as the collection of medical information by the government, the misuse of medical records in the private sector can range from merely annoying to causing irreparable harm.

Without a provision in a contract expressly forbidding the practice, some insurance companies may sell the names and addresses of individuals who have been prescribed certain medications to pharmaceutical companies so that the company can market its product to the patient. Such a practice may cause an inconvenience or annoyance to the individual, but it is not likely to cause irreparable harm. However, it should be the decision of the individual how medical information is shared, because when information gleaned from employee medical records is shared with employers without employee consent and hiring and firing or promotion decisions are based upon that information, irreparable harm may occur to the individual.

As a result, rather than seek treatment from their regular physician, some patients are already avoiding treatment or going to a physician and paying expenses out of pocket for a condition they would prefer to keep private. Requiring a physician to release medical information about a patient without the patient's consent would result in less-effective treatment of medical conditions

when a patient feels he cannot be open and honest with his doctor.

Conclusion. The privacy of medical records is becoming increasingly more important as medical science and technology develops. Through the use of electronic records, the compilation of comprehensive records is easier. The inappropriate use of those records by employers, insurance companies, individuals or the government can cause irreparable damage to a patient. Attempting to stop the compilation of medical records is like closing the lid on Pandora's box. The technology is available and the payoff is too high not to have the information. Therefore, it is critical that restraints be guaranteed to control the use of the information.

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⁴ Letter to U.S. Department of Health and Human Services by Congressman Ron Paul, December 9, 1999.