

Medical privacy

A bill in Congress would make all states protect patients' confidentiality

by Bob Roehr

Confidential sessions with therapists, treatment for sexually transmitted diseases, HIV test results—lesbians and gay men have long lived with the fear that personal medical information could become public, and shatter their lives.

We have been publicly humiliated, fired from our jobs, denied insurance and medical treatment, disowned by our families, and have even turned to suicide when those records have become known. Often there are no laws protecting the privacy of that most personal information, your medical records.

A 1993 report by the congressional Office of Technology Assessment called the current system of protecting patient confidentiality "a patchwork" of codes, state and federal laws that "is inadequate to guide the health-care industry."

Several factors are working to multiply the inadequacy of regulations. One is the trend for large corporations to run their own medical insurance programs rather than contract outside. Another is company "wellness programs." Both collect large amounts of medical and lifestyle data. Often those data are not protected and are used for personnel decisions such as promotions and firings.

But even when programs are contracted out, employers often have access to employees' records. Janlori Goldman, deputy director of the Center for Democracy and Technology, calls it "intolerable to support a system in which an employer's payment of a portion of an employee's health-care premiums, a normal part of most American employees' compensation packages, amounts to employers controlling their employees' health records."

The scattering of paper records in thousands of physicians' file cabinets seemed to offer some protection in the past, but an amalgamation of individual records into massive national electronic data banks is raising warning flags. "Since 1988, the percentage of health claims processed electronically has jumped from 8 percent to nearly 40 percent," said Sen. Nancy Kassebaum (R-Kan.).

Her comment came in opening remarks at a Nov. 14 hearing on a possible solution: the Medical Records Confidentiality Act of 1995 (S 1360).

The "Bennett-Leahy bill," as it is commonly called, is a strongly bipartisan measure. It has 17 initial co-sponsors and support of the leadership of both parties in the Senate.

Sen. Robert Bennett (R-Utah) was appointed by Majority Leader Bob Dole (R-Kan.) to head up a task force on health-care reform. "It startled me to learn that the average American has more control over and access to his or her credit information than to his or her medical information," he said.

Fourteen states have absolutely no privacy provisions for medical records, and protection in the others is spotty. Only 28 states allow patients to even view their own records, fewer still allow corrections of inaccurate information.

Bennett believes those differences make no sense in a time when "medical records are galloping toward the electronic age, crossing state lines literally with the speed of light."

Sen. Patrick Leahy (D-Vt.) called the right to privacy "one of our most cherished freedoms—it is the right to be left alone and to choose what we will reveal of ourselves and what we will keep from

others."

"I do not want advancing technology to lead to a loss of personal privacy and do not want the fear that confidentiality is being compromised to deter people from seeking medical treatment or stifle technological or scientific development," Leahy said.

The core of the bill will establish a minimal national standard for protecting the confidentiality of personal and identifiable health information.

It will limit primary use to treatment and payment on a need-to-know basis. Secondary use for public health, research and cost-containment purposes would generally be restricted to a format stripped of personal identifiers such as names and addresses.

Patients would be notified and asked for their consent to any release of data. An electronic trail of all those who access the data would be maintained.

The bill pre-empts much existing law but exempts certain stronger state laws (such as those regulating HIV disclosure in California and New York), the federal Alcohol and Drug Abuse Act, the Americans with Disabilities Act of 1990, and certain sections of the Ryan White CARE Act.

It establishes the principle of "trusteeship" for anyone who touches the records, and levies both civil and criminal penalties for violation of confidentiality. One of its biggest sticks is the power to ban

participation in Medicare, Medicaid and other federally funded health programs.

It provides for patients' access to their own health records and allows them to correct misinformation in those files.

The secretary of Health and Human Services will have six months from the date of passage to finalize regulations. The act will take effect six months after that.

Support for the concept of the legislation is almost universal. Consumers want privacy protection; industry above all else wants clear national standards. But all parties are pushing for changes to better reflect their interests.

Jeanne Schulte Scott, speaking for the Association for Electronic Health Care Transactions (the data processing industry), said that current language "does great harm to the health information service industry." She called for greater pre-emption of state law and fewer "trustee" responsibilities for their members as subcontractors.

The American Hospital Association questioned whether HHS should administer the act: "HHS, as a payer and administrator of health services, would also be subject to the requirements of this act. The dual role of regulator and regulated appears to be a conflict of interest."

Aimee Berenson, of the AIDS Action Council, recommended tightening access to medical files for research purposes to "research conducted at qualified medical facilities and institutions." She offered the model of regulations governing biomedical research funded by the National Institutes of Health.

She also wants the bill to "set out clear procedures for objecting to the release of medical records in civil litigation."

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