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Medical Privacy Still Unprotected In Health Information Technology Bill

Bill Ignores Need for Patient Control of Medical Records

Washington, DC--Despite efforts to introduce amendments to protect patient privacy in electronic medical records during House committee markup meetings on Thursday, June 15, 2006, Americans' medical records are still unprotected, said a national consumer medical privacy watchdog group.

Both the U.S. House Energy and Commerce Committee and U.S. House Ways and Means Committee held markup meetings for legislation to promote health information technology (HIT) today. Both committees voted against amendments that would expressly recognize the individual's right to medical privacy and provide privacy protections for data in electronic networks.

"Neither version of this HIT bill gives patients control over who can access their medical records, or the right to opt out of electronic systems. That leaves all Americans vulnerable to companies and individuals who want to use this very private information for reasons unrelated to healthcare or payment," said Deborah C. Peel, MD, Chairman, Patient Privacy Rights Foundation. "Building this system without privacy will open Pandora's Box."

In the Ways and Means Committee markup meeting, Reps. Doggett and Emanuel offered an amendment that would protect patient privacy in Rep. Nancy Johnson's bill H.R. 4157, the "Health Information Technology Promotion Act of 2006". In the Energy and Commerce markup meeting, Reps. Ed Markey and Lois Capps proposed an amendment that would protect privacy in Rep. Nathan Deal's Amendment to H.R. 4157, "Better Health Information Technology Promotion Act of 2006". Both amendments were voted down along party lines. It is anticipated that a combined version of H.R. 4157 will reach the House floor for a vote the week of June 19, 2006.

In April, Peel's Patient Privacy Rights and 25 other organizations, representing constituencies across the political and ideological spectrum, **urged the U.S. House of Representatives to build a patient-centered system with patient privacy rights at the core of any national HIT legislation.** Organizations including the Christian Coalition, the American Civil Liberties Union, Family Research Council and Consumer Action, urged Congress to include a number of privacy protections in legislation (see below).

"We are puzzled why the House can reach bipartisan agreement on bills to afford Americans protections of their financial data and to prevent identity theft, and yet not reach bipartisan agreement to protect patient's medical records," Peel said. "If you're bothered by the theft of 26.5 million Veterans' records, which included medical data and social security numbers, just wait until all 295 million Americans' records are in electronic medical files."

National research shows that Americans will avoid treatment, be less than truthful about symptoms, omit critical medical data and delay care if they are compelled to share their medical records over electronic health networks without adequate privacy safeguards.

"At least victims of identity theft, the fastest growing crime in America, can ultimately straighten out their credit and records over a year or two. Victims of medical privacy abuses will live with the consequences such as loss of jobs or insurance, discrimination, being denied access to schools, or getting sick because they've avoided healthcare for the rest of their lives," Peel said.

Peel said HIPAA had become a "disclosure rule" and was "toothless" since the adoption by the U.S. Department of Health and Human Services of a 2002 amendment to the privacy law, which permits over **600,000 health-related businesses and government agencies** to access personal health information without patient knowledge or permission. The amendment allows health care providers to share patient records with employers, drug and insurance companies, hospital corporations, marketing firms, credit reporting agencies, accountants, banks,

lawyers, and others without patient permission, and for business and other uses, unrelated to healthcare treatment or paying claims.

“Congresswoman Johnson’s bill further undermines patient control by allowing the Department of Health and Human Services (HHS) to eliminate all state healthcare privacy laws that generally are much stronger than HIPAA, the gutted federal Privacy Rule. Her own state, Connecticut, requires that patients give their consent before their medical records are released, while HIPAA has no such requirement,” said Peel.

Peel emphasized Patient Privacy Rights’ support for moving from paper to electronic medical records to improve health care and reduce costs, but not unless ironclad privacy and security protections are put in place first.

A total of 43 organizations have signed three separate Coalition for Patient Privacy letters to Congress, asking for basic privacy principles in HIT legislation:

- Recognize a patient's right to medical privacy
- Give patients control over who can access their personally identifiable health information across electronic health information networks
- Give patients the right to opt-in and opt-out of electronic systems
- Give patients the right to segment sensitive information
- Require audit trails of every disclosure of patient information and allow patients to review those disclosures
- Require that patients be notified of suspected or actual privacy breaches (The provisions in the Data Accountability and Trust Act should also apply to medical data.)
- Provide meaningful penalties and enforcement for privacy violations (Since February, 2005, over 52 million consumer records have been hacked.)
- Deny employers access to employees’ medical records
- Preserve stronger privacy protections in state laws (Ivo Nelson of IBM testified before an Energy and Commerce Health Subcommittee hearing in March that it would not be difficult to develop technology that follows individual state

patient privacy laws in an interoperable national health data network.)

See [coalition letters](#) to Ways and Means and Energy and Commerce committees.