

patientprivacyrights

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26 National Groups From Across Political Spectrum Combine Forces to Protect Medical Privacy

Urge Congress to Affirm Patient Control of Access to Medical Records in Health Information Technology Legislation

Washington, DC – As Congress moves rapidly to build a national electronic health system, a coalition of 26 organizations representing constituencies across the political and ideological spectrum urged the U.S. House of Representatives today to build a patient-centered system with patient privacy rights at the core of any national HIT legislation.

“Patients own their health data and should control who has access to their personal health records. Privacy violations will exponentially increase if patients cannot limit which health care businesses and government agencies can access our personal health data over an electronic network,” said Deborah C. Peel, MD, Chairman, Patient Privacy Rights Foundation, a national consumer medical privacy watchdog group. Patient Privacy Rights and 25 other organizations that share core principles of patient privacy signed and delivered a letter to Members of Congress in support of greater privacy protections to insure public trust in the proposed electronic national healthcare system.

“The intentions of the proposed health information technology legislation are to improve healthcare, reduce medical errors, and save money, but we believe that those benefits will be realized only if there are ironclad privacy protections,” said Tim Sparapani, Legislative Counsel, American Civil Liberties Union. “Guaranteeing privacy will generate public acceptance, trust and participation in these networks,” Sparapani said.

National research has shown 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.

“We don’t want our children to be denied entrance to schools or colleges, be denied their first jobs, be denied the opportunity to own their first home, or be denied insurance coverage because businesses have access to their medical records,” Tom McClusky, Director of Government Affairs, Family Research Council.

The U.S. Department of Health and Human Services eliminated patients’ rights to control access to their medical records in a 2002 amendment to the privacy law, which permitted over 800,000 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, 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.

“The federal ‘Privacy Rule’ is toothless,” said Dr. Peel. “It has become a ‘Disclosure Rule’. So, we urge Congress to put strong patient privacy protections into all HIT legislation they are considering.”

The 20 nationally recognized organizations are urging Congress to:

- Restore the patient's right of consent
- Give patients the right to opt-out of having their records in any national or regional electronic health system
- Give patients the right to segregate their most sensitive medical records
- Require audit trails of all disclosures
- Deny employers access to medical records
- Require that patients be notified of all suspected or actual privacy breaches
- Preserve stronger privacy protections in state laws
- Enact meaningful enforcement and penalties for privacy violators

The organizations making up the coalition are the following:

American Civil Liberties Union
American Conservative Union
Asian American Justice Center
California Consumer Health Care Council
Christian Coalition of America
Common Cause
Computer Professionals for Social Responsibility
Consumer Action
Electronic Privacy Information Center
Fairfax County Privacy Council
Family Research Council
Free Congress Foundation
National Asian Pacific American Families Against Substance Abuse
National Center for Transgender Equality
National Health Law Program
Patient Privacy Rights Foundation
Population Research Institute
Privacy Activism
Privacy Rights Now
Privacy Rights Clearinghouse
Republican Liberty Caucus
Right March.com
Thoughtful House Center for Autism
U.S. Bill of Rights Foundation
U.S. Public Interest Research Group
U.S. Public Policy Committee for the Association for Computing Machinery

About Patient Privacy Rights

Patient Privacy Rights is a national consumer watchdog organization based in Austin, TX. The mission of Patient Privacy Rights is to empower Americans to protect and preserve their human rights to medical privacy. Patient Privacy Rights believes Americans should have the right to decide who can see and use their medical records and is educating Americans about threats to patient privacy. They have launched an online petition for Americans to tell Congress “I Want My Medical Privacy”.

Web site: www.patientprivacyrights.org

“I Want My Medical Privacy” Petition: www.patientprivacyrights.org/petition