

COALITION FOR PATIENT PRIVACY

December 10, 2007

The Honorable
Edward Kennedy
United States Senate
317 Russell Senate Building
Washington D.C. 20510

The Honorable
Mike Enzi
United States Senate
379 Russell Senate Office Building
Washington, D.C. 20510

Dear Senators Kennedy & Enzi:

We applaud your efforts to advance health information technology as sponsors of the Wired for Healthcare Quality Act, S. 1693. The goal of encouraging health information technology and electronic health records is a good one. We would not oppose a bill that accomplished this AND built in protections to keep the most valuable information about us, our health, private.

Currently, the Wired Act does not accomplish both of these essential pieces. As such, on behalf of our respective organizations we continue to support the passage of this bill only if and when the Leahy amendments are adopted as a vital part of the Wired Act. Without both pieces the impact on our right to health privacy will be disastrous. We urge you to continue meaningful discussions with Sen. Leahy and include all of the privacy protections proposed in his amendment.

If asked, surely you would confirm that Americans should have a right to control our most personal and sensitive health information. Legislation such as the Wired Act should not move forward without safeguarding this essential right. Americans should have the ability to determine who can and cannot use, see and share our private health records.

Studies continue to reflect that an overwhelming majority of American consumers (86%) are somewhat or very concerned about the health industry's ability to protect the privacy of personal health information in deploying Electronic Health Records (EHRs).¹ It is very troubling to see the insurance and health industry trump our right to control who can see and use out most personal secrets.

Americans' personal health information currently is accessed and used without first obtaining informed consent. "Informed consent" means that the person whose health is affected must know and understand the risks involved in disclosing the information. **"Secondary" uses of**

¹ Consumer Attitudes Toward EMRs, EHRs, and the Privacy of Health Information. Health Industry Insights Poll at <http://www.healthindustry-insights.com/HII/getdoc.jsp?containerId=HI10012>

our health records, which have nothing to do with improving our health, have become the primary uses of our health records. The current language in the Wired Act will unfortunately make this practice even worse.

You cannot push Health IT now and come back to fix privacy later. When privacy is lost it is gone forever, there is no "delete" or "rewind" button.

We urge you to add the significant privacy provisions outlined in Sen. Leahy's amendment to the Wired Act in order to safeguard our health privacy and ensure our loved ones are not wrongfully denied opportunities because of an illness or genetic risk of disease. We look forward to working with you and your staff on this urgent problem.

Sincerely,

The Coalition for Patient Privacy

American Association of People with Disabilities www.aapd.org
American Civil Liberties Union www.aclu.org
American Conservative Union www.conservative.org
Clinical Social Work Association www.cswa.org
Consumers for Health Care Choices
Fairfax County Privacy Council www.fairfaxcountyprivacycouncil.org
Gun Owners of America www.gunowners.org
International Center for Disability Resources on the Internet www.icdri.org
Just Health www.justhealthnow.org
National Coalition of Mental Health Professionals & Consumers
Pain Relief Network www.painreliefnetwork.org
Patient Privacy Rights Foundation www.patientprivacyrights.org
Private Citizen, Inc. www.privatecitizen.com
U.S. Bill of Rights Foundation

"Anyone today who thinks the privacy issue has peaked is greatly mistaken...we are in the early stages of a sweeping change in attitudes that will fuel political battles and put once-routine business practices under the microscope." Forrester Research

cc: Every Member of the U.S. Senate

For additional information please contact:

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