

COALITION FOR PATIENT PRIVACY

May 19, 2008

Honorable Arlen Specter
United States Senate
711 Senate Hart Office Building
Washington, DC 20510-0001

Re: Oppose the Wired for Health Care Quality Act, S. 1693

Dear Senator Specter:

Attempting progress without sufficient privacy protections will undercut the overarching goals of building a trusted national health information technology (Health IT) system. The Coalition for Patient Privacy urges you to vote against the Wired for Health Care Quality Act, S. 1693. While the proposed privacy amendment to the "Wired Act" has some positive provisions, it does not go far enough to give Americans any assurances that their personal health records stay private.

The outcome of any Health IT legislation will truly impact Americans to the very core of their beings. Nothing is more personal than our health. Personal health information effects our reputations, our opportunities and those of our children and generations to come. As the consequences of mandating Health IT without privacy are so dire, we can only support the Wired Act if it incorporates the eleven Privacy Principles developed by our bi-partisan coalition of consumer advocacy organizations.

The 2007 Privacy Principles of the Coalition for Patient Privacy are:

- Recognize that patients have the right to health privacy
 - Recognize that user interfaces must be accessible so that health consumers with disabilities can individually manage their health records to ensure their medical privacy.
- The right to health privacy applies to all health information regardless of the source, the form it is in, or who handles it
- Give patients the right to opt-in and opt-out of electronic systems; i.e. the right for patients to give or withhold their consent for the use and disclosure of their health information.
 - Give patients the right to segment sensitive information
 - Give patients control over who can access their electronic health records
- Health information disclosed for one purpose may not be used for another purpose before informed consent has been obtained
- Require audit trails of every disclosure of patient information
- Require that patients be notified promptly of suspected or actual privacy breaches
- Ensure that consumers cannot be compelled to share health information to obtain employment, insurance, credit, or admission to schools, unless required by statute
- Deny employers access to employees' health records before informed consent has been obtained

- Preserve stronger privacy protections in state laws
- No secret health databases. Consumers need a clean slate. Require all existing holders of health information to disclose if they hold a patient's health information
- Provide meaningful penalties and enforcement mechanisms for privacy violations detected by patients, advocates, and government regulators

We believe these principles are essential to protect Americans' private health records and are essential for quality health care. If we fail to protect the individual's right to privacy of the most intimate and confidential personal data, the individual will be selective in providing information. When patients avoid telling their physician everything they should, it compromises treatment and can cause "bad" outcomes, including the creation of electronic health records that are inaccurate, incomplete, and possibly dangerously misleading

Moreover, without these basic privacy principles as the foundation of Health IT systems, Americans are open to widespread discrimination. Self-insured employers can deny promotions or jobs. Insurers, including those offering health, life and property, car, mortgage and other kinds of insurance, can set higher rates or deny coverage altogether. Schools can refuse admission to students with chronic illnesses or histories of depression. Banks can decline loans or charge more for credit.

Legislation that will cause so much harm and deny opportunities to so many worthy Americans, whether intended or not, surely deserves extensive public hearings. We encourage you to hold hearings on health privacy issues in the appropriate Senate committees at the earliest possible time.

Please stand up for your constituents' privacy and that of your own; do not allow the Wired Act to be "hotlined" in the Senate. We appreciate your leadership and hope you will restore Americans' longstanding rights to control personal health information. We look forward to working with you and your staff.

Sincerely,

The Coalition for Patient Privacy

American Association of Practicing Psychiatrists
American Civil Liberties Union
Citizens' Council on Health Care
Clinical Social Work Association
Just Health (CA Consumer Health Care Council)
The Multiracial Activist
Patient Privacy Rights
Greg Scandlen, Health Advocate

American Psychoanalytic Association
Children's Birthright Trust
Citizens for Health
Consumer Action
The Liberty Coalition
Pain Relief Network
Private Citizen, Inc.
U.S. Bill of Rights Foundation

For additional information please contact:

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