

COALITION FOR PATIENT PRIVACY

February 2, 2009

Honorable Harry Reid
Majority Leader
United States Senate
522 Hart Senate Office Building
Washington, DC 20510

Dear Senator Reid:

Congress has taken critical steps to protect Americans' jobs and opportunities by including essential privacy protections with the promotion of health information technology (health IT) in the American Recovery and Reinvestment Act, S.1. These common sense consumer protections address many of the issues that the Coalition for Patient Privacy, representing millions of Americans, brought to your attention. *The protections in the bill are the bare minimum required to accomplish two critical goals:*

- 1) **Ensure consumer confidence with health IT, thereby protecting our \$20 billion investment.**
- 2) **Ensure that above all we "do no harm" to patients when using their most intimate information in the digital age.**

We all want to innovate and improve health care. This simply cannot occur without consumer confidence that their private medical records are protected and under their control. We urge you to maintain the practical consumer protections that both consumer and privacy advocates strongly support and reject calls from industry to spend taxpayer dollars without accountability, control or transparency. We should not continue to allow business as usual when it harms the American public. In fact, the only way to achieve President Obama's vision for health care and health IT is to ensure privacy now.

By far the most important provision is the prohibition on the sale of protected health information (SEC. 13405(e)). Personal health information should not be sold and shared as a typical commodity. Health information is different; it is extremely sensitive and can directly impact jobs, credit, and insurance coverage. It is critical to put a stop to current data sales and misuse, but also to prevent the development of future businesses that sell personal health information as a commodity while doing nothing to improve Americans' health.

All additional privacy provisions in S. 1 provide an important piece in protecting individuals. These include:

- Limitations on marketing, audit trails of electronic health record transactions, requiring the Secretary to revisit and narrow the definition of "health care operations", and rights to electronic copies of our records;

- Improved enforcement provisions such as breach notification, required periodic audits, state attorneys general enforcement, a compensation scheme for privacy victims and applying security and privacy provisions and penalties to business associates;
- Requiring the HIT Policy Committee to make recommendations regarding segmentation of specific and sensitive information;
- Funding for consumer advocacy groups and not for profit entities to participate in the regulatory process and a study of health technology that can be used to meet the needs of seniors and individuals with disabilities.

We also support the provision included in the House bill that was proposed by Congressman Markey, SEC. 3002(b)(2)(B)(vi) that requires the HIT Policy Committee to make recommendations regarding technologies that allow individually identifiable health information to be rendered unusable, unreadable, or indecipherable to unauthorized individuals when transmitted or physically transported.

There is no more sensitive information on earth than our health records. Congress will need to build on the basic privacy protections in this bill and we move forward. We continue to advocate that our right to health information privacy be explicitly reaffirmed in statute, and much more can be done to ensure Americans have greater control over the uses of their health information. Nevertheless, the privacy provisions included in the bill are critical first steps to protecting consumers. We **must** couple health IT promotion with privacy protections. Working together we are making great progress and we thank you for your commitment to protect consumers.

Sincerely,

The Coalition for Patient Privacy

cc: United States Senate

The Coalition for Patient Privacy

AIDS Action
Alliance for Patient Safety
American Association of People with
Disabilities
American Foundation for the Blind
Bill of Rights Defense Committee
Citizens for Health
Citizen Outreach Project
Clinical Social Work Association
Confederation of Independent Psychoanalytic
Societies
Consumer Action
Ethics in Government Group

Fairfax County Privacy Council
Georgians for Open Government

Government Accountability Project
Health Integrity Project
International Association of Whistleblowers
Just Health
The Multiracial Activist
National Center for Transgender Equality
National Coalition for Mental Health
Professionals & Consumers
New Grady Coalition
Patient Privacy Rights

Private Citizen, Inc.
Student Health Integrity Project
Tolven
U.S. Bill of Rights Foundation