

patientprivacyrights

December 22, 2008

The Honorable Harry Reid
Office of the Majority Leader
United States Senate
S-221 Capitol Building
Washington, DC 20510-7020

The Honorable Nancy Pelosi
Office of the Speaker
United States House of Representatives
H-232 Capitol Building
Washington, DC 20515

Dear Majority Leader Reid and Speaker Pelosi:

We welcome the renewed commitment in Congress and by the President-elect to protecting consumers over special interests. As we all work together to incorporate health IT in the economic stimulus package, we urge you to ensure our nation's health IT system does not put Americans' jobs, access to health care and credit at risk by dismissing the need for privacy. *Patients' trust is essential* to health IT adoption and participation, and only attainable if the legislation builds privacy into the health IT system.

At the heart of the argument is whether we have learned anything from the last few years of letting industry set its own rules. Clearly, greed and a complete lack of stewardship and respect for the average American caused much of the ruin of our financial sectors. Now we are all paying a very painful price for a failure to protect consumers and letting the financial industry steer the ship.

We must not repeat the same mistake with the health industry. A coalition of "health plans, pharmaceutical companies, vendors, employers, health product distributors, pharmacy benefit managers" and others are advocating that we invest billions in health IT without *ANY* protections for consumers. Notably absent from this coalition are patients and doctors, those who stand to lose the most when personal control over health information is eliminated and sensitive health data is sold and used in ways that do not help doctors to improve our health.

Please do not let for-profit corporations, entities with a duty to their shareholders to make money, call the shots. Health IT without privacy is an excellent way to establish a goldmine of information that can be used to:

- increase profits
- promote expensive – not necessarily more effective – drugs, devices, and treatments
- cherry pick patients who are cheaper to ensure and treat while not providing for the remainder; and
- market directly to consumers.

These are not the goals of Patient Privacy Rights, members of the Coalition for Patient Privacy, or members of Congress. ***We want to innovate and improve health care for our country, and that can be done only with respect for our democracy's right to privacy.***

We urge you to ensure accountability, control and transparency with health IT, and this must be addressed within the same piece of legislation. To do otherwise is akin to handing over a blank check to AIG, Citigroup or Ford Motor Company.

At a minimum, please support:

ACCOUNTABILITY – Hold every entity with access to health information accountable.

We have learned the painful lessons of letting industry set its own rules. Consumers no longer trust that corporations will only use personal health information as directed or guard it from theft or loss.¹

- Those who hold or store personal health information should ensure that the data is accurate, reliable and secure.² Minimum standards should include requirements for: encrypting data in database storage and in transit, limiting access to specific individuals via informed, facilitating electronic consent, and building in audit trails of all electronic transactions.
- Congress should authorize and fund Health & Human Services (HHS) and the Federal Trade Commission (FTC) to increase their oversight of data flow and sharing practices including funds for undertaking random audits of contracts. Require breach notification and whistleblower protections.

CONTROL – Ensure individuals control the use of personal health information.

An individual's right to control how their personal information is used is fundamental to the Code of Fair Information Practices and most professional codes of ethics; the same code should apply to our most sensitive information, our health records.

- Codify a federal right to health information privacy.
- All systems should ensure individuals can segment sensitive information so safeguards are built in up front.
- Provide incentives for health IT systems to use electronic informed consent and innovative consumer privacy controls.

TRANSPARENCY – Protect consumers from abusive practices.

Personal health information should not be sold and shared as if it were some other commodity like stocks or mortgages.³ Health information is significantly different from other data collected

¹ Since 2005 over 45 million health records were breached and 250,000 Americans' health identities were stolen.

² Code of Fair Information Practices, Principle 5

³ See "Evidence of Disclosure," http://www.patientprivacyrights.org/site/DocServer/Evidence_of_Disclosure.pdf?docID=4501

by marketers and data miners; it is especially sensitive and can directly impact jobs, credit, and insurance coverage.

- Prohibit direct or indirect remuneration for the sharing, disclosure or use of personal health information with limited exceptions for research and public health.
- Ensure that corporations cannot obtain exclusive or contractual rights to own or control personal health information.⁴
- Personal health information obtained for one purpose must not be used or made available for other purposes without informed consent.⁵ We strongly support provisions re-defining and limiting the broad category of “Health Care Operations.”

All of us are working steadfastly to ensure the best outcomes for health IT within the time and process constraints of a fast-tracked stimulus package. In light of lessons learned and the dramatic consequences we continue to face in our economy, now is not the time to be shortsighted in our policy. We commend you for all your hard work and look forward to working with you to ensure our nation promotes both health IT and privacy.

Sincerely,

/s/

Deborah Peel, MD
Founder & Chair

/s/

Ashley Katz, MSW
Executive Director

About Patient Privacy Rights:

As the nation’s health privacy watchdog, Patient Privacy Rights works to ensure that we don’t have to choose between privacy and health care or health IT. Patient Privacy Rights is a 501(c)3 nonprofit headquartered in Austin, Texas with an office in Washington D.C., funded solely by individuals. Founded by a practicing physician, our mission is to ensure Americans control access to their personal health information so that we progress with privacy. When our most intimate information can be sold and shared with the click of a mouse, many may lose opportunities for work, wealth and well being.

Patient Privacy Rights leads the bi-partisan Coalition for Patient Privacy, representing nearly 12 million Americans and including over 50 consumer organizations and technology corporations such as the ACLU, American Conservative Union, American Association for People with Disabilities, AIDS Action, Family Research Council and Microsoft.

⁴ For example, CVS Caremark’s *iScribe* electronic prescribing program obtains absolute rights to all data inputted into their system via their service agreement with providers allowing them to sell or share the data with third party partners including drug manufacturers, healthcare clearinghouses and data analysis companies.

⁵ Code of Fair Information Practices, Principle 3