

COALITION FOR PATIENT PRIVACY

“A.C.T.” for Privacy in 2009

January 14, 2009

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

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

Dear Speaker Pelosi and Senator Reid:

Our bi-partisan Coalition, representing millions of Americans, urges you to ensure that we develop a health IT system that protects our health, jobs and privacy. We welcome the renewed commitment in Congress to protecting consumers over special interests. Consumer trust is essential to health IT adoption and participation, and only attainable with privacy.

In order to achieve a successfully wired health care system that Americans trust, we ask you, as a member of Congress, to “A.C.T.” now to ensure our information is only used to promote health:

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 use personal health information only as directed or guard it from theft or loss.

- Those who collect, store or use personal health information should help ensure that the data is accurate, reliable and secure. Minimum standards should include: encrypting data at rest and in transit, limiting access to specific individuals via informed, electronic consent and audit trails of all electronic transactions.
- Authorize and fund Health & Human Services and the Federal Trade Commission to increase their oversight of industry practices including random audits of contracts.
- Require breach notification, privacy safeguards and whistleblower protections, including meaningful enforcement of privacy rights.

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

Fundamental to the Code of Fair Information Practices and most professional Codes of Ethics is an individual’s right to control how their personal information is used.

- Codify a federal right to health information privacy.
- Ensure individuals can segment sensitive information and that safeguards for medical information are built in up front before problems arise.
- Provide incentives for health IT systems to use electronic informed consent, innovative consumer privacy controls and for user interfaces to be accessible for patients with disabilities.

TRANSPARENCY – Protect consumers from abusive practices.

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. Commercial transfers undermine routine privacy safeguards, including transparency and accountability.

- 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. We have evidence that selling of this data is happening at major companies (details available upon request).
- Personal health information obtained for one purpose must not be used for other purposes without informed consent. Even when consent is obtained, privacy obligations such as security and prevention of misuse, continue.

Progress for health IT and privacy is being made! We hope you will join our Coalition in protecting the right to privacy for consumers, employees, and providers.

Sincerely,

The Coalition for Patient Privacy: [Signing Organizations on following page]

cc: Members of the U.S. House of Representatives
Members of the U.S. Senate

For more information please contact:

Ashley Katz
akatz@patientprivacyrights.org
(O) (512) 732-0033
(M) (512) 897-6390

AIDS Action Council
www.aidsaction.org

Alliance for Patient Safety
www.allianceforpatientsafety

American Association for People with Disabilities
www.aapd.org

American Civil Liberties Union
www.aclu.org

Arizona Eagle Forum

Bazelon Center for Mental Health Law

Bill of Rights Defense Committee
www.bordc.org

Citizens for Health
www.citizens.org

Citizen Outreach Project

Clinical Social Work Association
www.clinicalsocialworkassociation.org

Confederation of Independent Psychoanalytic Societies

Consumer Action
www.consumer-action.org

Cyber Privacy Project

Esther Dyson
www.edventure.com

Electronic Privacy Information Center
www.epic.org

Fairfax County Privacy Council
www.fairfaxcountyprivacycouncil.org

Government Accountability Project
www.whistleblower.org

Health Administration Responsibility Project, Inc.
www.harp.org

International Association of Whistleblowers
www.internationalassociationofwhistleblowers.net

Senator Karen Johnson (AZ)

JustHealth
www.justhealthnow.org

Justice Through Music
www.jtmp.org

Liberty Coalition
www.libertycoalition.net

Microsoft Corporation, Inc.
www.microsoft.com

The Multiracial Activist
www.multiracial.com

National Association of Social Workers
www.socialworkers.org

National Center for Transgender Equality
www.NCTEquality.org

The National Coalition for Mental Health Professionals and Consumers
www.thenationalcoalition.org

National Workrights Institute
www.workrights.org

Patient Privacy Rights
www.patientprivacyrights.org

Private Citizen, Inc.

Representative Cindy Rosenwald (NH)

Bruce Schneier
www.schneier.com

Tolven
www.tolven.org

U.S. Bill of Rights Foundation

Velvet Revolution
www.velvetrevolution.us