

# Coalition for Patient Privacy

April 5, 2006

## Via Facsimile and Hand Delivered

The Honorable William M. Thomas  
Chair  
Committee on Ways and Means  
Washington, DC

The Honorable Charles B. Rangel  
Ranking Minority Member  
Committee on Ways and Means  
Washington, DC

The Honorable Joe Barton  
Chair  
Committee on Energy and Commerce  
Washington, DC

The Honorable John D. Dingell  
Ranking Minority Member  
Committee on Energy and Commerce  
Washington, DC

The Honorable Nancy L. Johnson  
Chair  
Subcommittee on Health,  
Committee on Ways and Means  
Washington, DC

The Honorable Fortney H. "Pete" Stark  
Ranking Minority Member  
Subcommittee on Health,  
Committee on Ways and Means  
Washington, DC

The Honorable Nathan Deal  
Chair  
Subcommittee on Health,  
Committee on Energy and Commerce  
Washington, DC

The Honorable Sherrod Brown  
Ranking Minority Member  
Subcommittee on Health,  
Committee on Energy and Commerce  
Washington, DC

Dear Representative:

We, the undersigned organizations, applaud your efforts toward bringing the American healthcare system into the 21st Century by using technology to control costs and to reduce medical errors. Yet, we urge you to build a patient-centered system with patient privacy rights as the core of the health IT system.

We believe that the benefits technology can bring will be fully realized only if the health IT system is built upon the foundation of medical ethics and patient control of access to their sensitive identifiable medical records. The privacy standards in state and common law, Constitutional law, and medical ethics must be incorporated into the design of all regional and national health IT systems and networks.

Americans must trust the health IT system, must have confidence in the security of the system and must continue to trust their healthcare providers. Unless patients are assured of security, they will avoid treatment, lie about their symptoms and health issues, omit critical medical data, and delay care, endangering their health and the health of others because they know that their records will be used and shared without their permission.

The proper balance to ensure timely access to medical records for treatment and preserve patient control of medical records means allowing access in emergencies if consent cannot be obtained, but requiring patient permission before records are disclosed in everyday situations.

Without control, patients will not use the healthcare system in an effective manner, if at all, driving up costs and increasing the danger to everyone. Further, if they do not trust the privacy of electronic data systems and networks, their data will be incomplete and filled with inaccuracies and omissions. Corrupted, incomplete and false data will not enhance or improve medical outcomes or research.

We urge you to build a foundation for medical information technology that is based on the following longstanding ethical and privacy principles and protections:

- Restore the patient's right of consent
- Give patients the right to opt-out of having their records in any national or regional electronic health system
- Give patients the right to segregate their most sensitive medical records
- Require audit trails of all disclosures
- Deny employers access to medical records
- Require that patients be notified of all suspected or actual privacy breaches
- Preserve stronger privacy protections in state laws
- Enact meaningful enforcement and penalties for privacy violators

Sincerely,

American Civil Liberties Union  
American Conservative Union  
Asian American Justice Center  
California Consumer Health Care Council  
Christian Coalition of America  
Common Cause  
Computer Professionals for Social Responsibility  
Consumer Action  
Electronic Privacy Information Center  
Fairfax County Privacy Council  
Family Research Council  
Free Congress Foundation  
National Asian Pacific American Families Against Substance Abuse  
National Center for Transgender Equality  
National Health Law Program  
Patient Privacy Rights Foundation  
Population Research Institute  
Privacy Activism  
Privacy Rights Now  
Privacy Rights Clearinghouse  
Republican Liberty Caucus  
Right March.com  
Thoughtful House Center for Autism  
U.S. Bill of Rights Foundation  
U.S. Public Interest Research Group  
U.S. Public Policy Committee for the Association for Computing Machinery

cc: Every Member of the U.S. House of Representatives

For additional information, contact:

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American Civil Liberties Union, [www.aclu.org](http://www.aclu.org)  
American Conservative Union, [www.conservative.org](http://www.conservative.org)  
Asian American Justice Center, [www.advancingequality.org](http://www.advancingequality.org)  
California Consumer Health Care Council, [www.cchcc.org](http://www.cchcc.org)  
Christian Coalition of America, [www.cc.org](http://www.cc.org)  
Common Cause, [www.commoncause.org](http://www.commoncause.org)  
Computer Professionals for Social Responsibility, [www.cpsr.org](http://www.cpsr.org)  
Consumer Action, [www.consumer-action.org](http://www.consumer-action.org)  
Electronic Privacy Information Center, [www.epic.org](http://www.epic.org)  
Fairfax County Privacy Council, [www.FairfaxCountyPrivacyCouncil.org](http://www.FairfaxCountyPrivacyCouncil.org)  
Family Research Council, [www.frc.org](http://www.frc.org)  
Free Congress Foundation, [www.freecongress.org](http://www.freecongress.org)  
National Asian Pacific American Families Against Substance Abuse, [www.napafasa.org](http://www.napafasa.org)  
National Center for Transgender Equality, [www.nctequality.org](http://www.nctequality.org)  
National Health Law Program, [www.healthlaw.org](http://www.healthlaw.org)  
Patient Privacy Rights Foundation, [www.patientprivacyrights.org](http://www.patientprivacyrights.org)  
Population Research Institute, [www.pop.org](http://www.pop.org)  
Privacy Activism, [www.privacyactivism.org](http://www.privacyactivism.org)  
Privacy Rights Now, [www.privacyrightsnow.com](http://www.privacyrightsnow.com)  
Privacy Rights Clearinghouse, [www.privacyrights.org](http://www.privacyrights.org)  
Republican Liberty Caucus, [www.rlc.org](http://www.rlc.org)  
Right March.com, [www.rightmarch.com](http://www.rightmarch.com)  
Thoughtful House Center for Autism, [www.thoughtfulhouse.org](http://www.thoughtfulhouse.org)  
U.S. Bill of Rights Foundation, [www.usbor.org](http://www.usbor.org)  
U.S. Public Interest Research Group, [www.uspirg.org](http://www.uspirg.org)  
U.S. Public Policy Committee for the Association for Computing Machinery, [www.acm.org](http://www.acm.org)

