

# COALITION FOR PATIENT PRIVACY

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November 24, 2009

David Blumenthal, MD, MPP  
National Coordinator  
Office of National Coordinator for Health Information Technology  
U. S. Department of Health and Human Services  
200 Independence Avenue, SW  
Washington, DC 20201

Dear Dr. Blumenthal:

We were very pleased to hear your announcement last month regarding a new privacy and security work group that will advise the HIT Policy Committee and “create recommendations based on results of the September privacy hearing.” Our Coalition and the millions of Americans we represent solidly stand behind the remarks Dr. Latanya Sweeney and Dr. Deborah Peel made at the September privacy hearing. Americans clearly want to control their personal health information and, more importantly, they expect the federal government to ensure this happens.

We have been provided no evidence that control or *meaningful, informed consent* does not work. In fact, the final report from the Agency for Healthcare Research and Quality that describes their recent nationwide focus groups clearly illustrates that the public expects the right to decide who can see and use their personal health information. AHRQ determined there was no support for the establishment of general rules that apply to all health care consumers. Participants thought that health care consumers should be able to exert control over their own health information **individually, rather than collectively**<sup>1</sup>. The Administration has a duty to respect and to protect these fundamental privacy rights.

From the outside looking in, we note the HIT Policy Committee has an extensive and difficult job description and seemingly unrealistic time constraints. It is critical that individual experts outside this Committee be an integral part of the privacy and security work group, as Congress intended in HITECH. The work simply cannot be done without reaching out to other experts in health privacy and national consumer privacy advocacy organizations.

Therefore, we urge you to cast a broad net when selecting members of this critical work group. Many privacy and consumer experts that have a wealth of knowledge on HIT and privacy are eager to serve this endeavor. We hope you will call on members of our Coalition, including Dr. Peel, along with HIT vendors implementing innovative privacy solutions.

We support your efforts and continue to offer our expertise and time.

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<sup>1</sup> AHRQ Publication No. 09-0081-EF “Final Report: Consumer Engagement in Developing Electronic Health Information Systems” Prepared by: Westat, (July 2009), see page 29, [http://healthit.ahrq.gov/portal/server.pt/gateway/PTARGS\\_0\\_1248\\_888520\\_0\\_0\\_18/09-0081-EF.pdf](http://healthit.ahrq.gov/portal/server.pt/gateway/PTARGS_0_1248_888520_0_0_18/09-0081-EF.pdf) (last visited September 14, 2009)

Sincerely,

**The Coalition for Patient Privacy**

American Association of People with Disabilities  
American Civil Liberties Union  
American Council for the Blind  
Clinical Social Work Association  
Consumer Action  
Electronic Privacy Information Center  
Just Health  
The Multiracial Activist  
National Association of Social Workers  
National Coalition of Mental Health Professionals and Consumers  
Patient Privacy Rights  
Private Citizen, Inc.  
Secure ID Coalition  
U.S. Bill of Rights Foundation  
Universata, Inc.

cc:

HIT Policy Committee Members  
HIT Standards Committee Members

For additional information, please contact:

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