## **National Committee on Vital and Health Statistics** Subcommittee on Privacy, Confidentiality & Security

#### "Personal Health Records"

May 20 - 21,2009

**Hubert H. Humphrey Building** 

**Room 800** 

200 Independence Ave, SW Washington, D.C. 20201

June 9, 2009

**National Center for Health Statistics** 

**Auditorium** 

3311 Toledo Road

Hyattsville, MD 20782

#### **AGENDA**

Wednesday, May 20, 2009

9:00 – 9:15 a.m. **Introductions and Opening Remarks** Leslie P. Francis, Ph.D., J.D, Co-chair

John Houston, J.D., Co-chair

9:15 - 10:45 a.m. Panel I - What Will Consumer-Robert L. Coffield, J.D.

Facing Health IT Look Like in 5 or 10

vears?

Flaherty, Sensabaugh & Bonasso, PLLC

Jane Sarasohn-Kahn, M.A., M.H.S.A.

THINK-Health

Daniel J. Weitzner, J.D.

Policy Director, Technology and Society

World Wide Web Consortium

10:45 - 11:00 a.m. Break

Panel II - What Will Consumer-11:00 – 12:30 p.m. Josh Lemieux

Facing Health IT Look Like in 5 or 10

years? (cont'd)

Director of Personal Health Technology Connecting for Health, Markle Foundation

Donald T. Mon, Ph.D.

Vice President of Practice Leadership American Health Information Management

Association

James Allen Heywood Co-founder and Chairman

PatientsLikeMe

12:30 – 1:30 p.m. Lunch

Panel III - PHRs Offered by Non-1:30 - 3:00 p.m. Marc Donner, Ph.D.

#### **Provider/Plan Entities**

Director of Engineering

Google Health

Colin Evans

Chief Executive Officer Dossia Consortium

Philip Marshall, M.D., M.P.H. Vice President, Product Strategy

WebMD Health

Michael Stokes, M.S.

Director of Policy and Compliance

Health Solutions Group Microsoft Corporation

3:00 - 3:15 p.m. Break

3:15 – 3:45 p.m. Statements from members of the public

3:45-4:45 p.m. Discussion

4:45 - 5:00 p.m. Administrative announcements and

prepare for Day 2

5:00 p.m. Recess until May 21

#### **Thursday, May 21, 2009**

9:00 – 9:15 a.m. Introductions and Opening Remarks Leslie P. Francis, Ph.D., J.D, Co-chair

John Houston, J.D., Co-chair

9:15 – 10:45 a.m. Panel IV: Plans and PHRs Joy M. Grossman, Ph.D.

Senior Health Researcher

Center for Studying Health System Change

Christopher B. Sullivan, Ph.D.

Administrator, Office of Health Information

Technology

Florida Agency for Health Care Administration (via phone)

Bruce H. Taffel, M.D.

Vice President, Chief Medical Officer

Shared Health

#### 11:00 – 12:30 p.m. **Panel V – Providers and PHRs**

Gail L. Graham, RHIA Director of Health Data and Informatics Veterans Health Administration

Anna-Lisa Silvestre, M.P.H. Vice President, Online Services Kaiser Permanente HealthConnect

Department of Veterans Affairs

James M. Walker, M.D., FACP Chief Health Information Officer Geisinger Health System

Matthew K. Wynia, M.D., M.P.H. Director of the Institute for Ethics *American Medical Association* 

12:30 – 12:50 p.m. Lunch Break

12:50 – 2:00 p.m. Working Lunch/Discussion

2:00 p.m. Recess until June 9, 2009

### Tuesday, June 9, 2009

9:00 – 9:15 a.m. Introductions and Opening Remarks Leslie P. Francis, Ph.D., J.D, Co-chair John Houston, J.D., Co-chair

9:15 – 10:45 a.m. **Panel VI – Federal Demonstration** Patrick Conway, M.D.

ProjectsOffice of the Assistant Secretary for Planningand Evaluation, HHS

(for Medicare PHR Choice pilot in Utah and

Arizona)

Seth Edlavitch, M.P.H., M.H.A. Program Manager & Project Director *My Personal Health Record, South Carolina* (MyPHRSC)

Chrislyn Gayhead, B.S.N., R.N. Office of e-Health and Standards Centers for Medicare and Medicaid Services, HHS (for MyPHRSC)

# 11:00 – 12:30 p.m. **Panel VII – Consumer Advocates and Attitudes**

Susannah Fox Associate Director, Digital Strategy Pew Research Center

Dave deBronkart (Blogger "e-Patient Dave") Co-chair, *Society for Participatory Medicine* 

Deven McGraw, J.D. Director, Health Privacy Project Center for Democracy and Technology

Robert Gellman, J.D. Independent Privacy Consultant, and Author, "Personal Health Records: Why Many PHRs Threaten Privacy" World Privacy Forum

12:30 – 1:30 p.m. Lunch

1:30 – 1:45 p.m. Statements from members of the public

1:45 – 3:00 Discussion

3:00 - 3:15 p.m. Break

3:15-3:45 p.m. Discussion

4:45 - 5:00 p.m. Plan next steps

5:00 p.m. Adjournment

Times, topics and speakers are subject to change. For final agenda, please call 301-458-4200 at NCHS or visit the NCVHS Home Page at http://ncvhs.hhs.gov.

All visitors at the Hubert H. Humphrey Building and the National Center for Health Statistics must be a citizen of the United States unless they have made prior advance arrangements to attend. Please bring valid photo identification.