
Secretary's Advisory Committee on Genetics, Health, and Society

Twenty-first Meeting
February 4-5, 2010
Washington, D.C.

DRAFT AGENDA

Thursday, February 4, 2010

8:30 a.m. – 8:45 a.m. Opening Remarks
Steven Teutsch, M.D., M.P.H.
SACGHS Chair

Preliminary Planning for Session on the Affordable Genome

8:45 a.m. – 9:15 a.m. Discussion of June 2010 SACGHS Session on the Implications of Affordable
Whole-Genome Sequencing
Dr. Teutsch
SACGHS Chair

Clinical Utility and Comparative Effectiveness

9:15 a.m. – 9:45 a.m. Update on the Clinical Utility and Comparative Effectiveness Task Force
Marc Williams, M.D.
SACGHS Member

9:45 a.m. – 10:00 a.m. BREAK

Genetics Education and Training

10:00 a.m. – 11:45 p.m. Public Consultation Draft Report on Genetics Education and Training and
Draft Recommendations

10:00 a.m. – 10:30 a.m. Overview of Draft Report and Draft Recommendations
Barbara Burns McGrath, R.N., Ph.D.
SACGHS Member

10:30 a.m. – 10:45 a.m. Briefing on the Secretary's Advisory Committee on Heritable Disorders in
Newborns and Children (ACHDNC) Education Subcommittee
Jana Monaco
Co-Chair, Education and Training Subcommittee, ACHDNC

10:45 a.m. – 11:45 a.m. Committee Discussion

Public Comment Session

11:45 a.m. – 12:15 p.m. Public Comments

12:15 p.m. – 1:15 p.m. LUNCH

Genomic Data Sharing

1:15 p.m. – 5:30 p.m. Genomic Data Sharing—Objectives, Mechanisms, and Policies

1:15 p.m. – 1:20 p.m. Introduction
Charmaine Royal, Ph.D.
SACGHS Member

1:20 p.m. – 1:40 p.m. Review of Federal Activities Related to Genomic Data Sharing
Laura Lyman Rodriguez, Ph.D.
Acting Director, Office of Policy, Communications, and Education
National Human Genome Research Institute

1:40 p.m. – 1:55 p.m. Committee Discussion

1:55 p.m. – 4:05 p.m. Genomic Data Sharing Models

1:55 p.m. – 2:15 p.m. *Health Care Systems Model*
Catherine Schaefer, Ph.D.
Executive Director, Research Program
Kaiser Permanente

2:15 p.m. – 2:35 p.m. *Academic Model*
Daniel Masys, M.D.
Professor and Chair, Biomedical Informatics
Vanderbilt University

2:35 p.m. – 2:55 p.m. *Government Model*
Laura Lyman Rodriguez, Ph.D.
Acting Director, Office of Policy, Communications, and Education
National Human Genome Research Institute

2:55 p.m. – 3:15 p.m. *Commercial Model*
Mark Hoffman, Ph.D.
Director, Translational Medicine
Cerner Corporation

3:15 p.m. – 3:35 p.m. *Consumer-Controlled Model*
Robert H. Shelton, M.B.A.
Co-Founder, Chairman, Chief Executive Officer
Private Access, Inc.

3:35 p.m. – 4:05 p.m. Committee Discussion

4:05 p.m. – 4:20 p.m. BREAK

- 4:20 p.m. – 4:35 p.m. Future Directions in Health Information Technology
Joyce Mitchell, Ph.D.
Professor and Chair, Department of Biomedical Informatics
University of Utah School of Medicine
- 4:35 p.m. – 4:50 p.m. Committee Discussion
- 4:50 p.m. – 5:20 p.m. Committee Discussion of Next Steps
- 5:20 p.m. – 5:30 p.m. Summation of Session
Dr. Royal
- 5:30 p.m. – 5:35 p.m. Closing Remarks – Dr. Teutsch

Friday, February 5, 2010

- 8:30 a.m. – 8:45 a.m. Opening Remarks
Dr. Teutsch
SACGHS Chair

Gene Patents and Licensing Practices

- 8:45 a.m. – 9:00 a.m. Overview of Revised SACGHS Report *Gene Patents and Licensing Practices and Their Impact on Patient Access to Genetic Tests*
Dr. Teutsch
SACGHS Chair
- 9:00 a.m. – 10:45 a.m. Discussion and Coming to Closure
- 10:45 a.m. – 11:00 a.m. BREAK

Public Comment Session

- 11:00 a.m. – 11:30 a.m. Public Comments
- 11:30 a.m. – 12:30 p.m. LUNCH

Updates from Federal Agencies

- 12:30 p.m. – 2:15 p.m. Update of Federal Activities
- 12:15 p.m. – 12:35 p.m. Office of the National Coordinator for Health Information Technology
Speaker TBC
- 12:35 p.m. – 12:55 p.m. MEDCAC Meeting on Pharmacogenomic Testing for Anticancer Therapies
Jeffrey Roche, M.D., M.P.H.
Coverage & Analysis Group, Office of Clinical Standards and Quality
Centers for Medicare & Medicaid Services

- 12:55 p.m. – 1:15 p.m. AHRQ Evidence-Based Reports Relevant to Genetic Testing
Gurvaneet Randhawa, M.D., M.P.H.
Center for Outcomes and Evidence
Agency for Healthcare Research and Quality
- 1:15 p.m. – 1:35 p.m. Development of Genomics Objectives for Healthy People 2020
Muin Khoury, M.D., Ph.D.
National Office of Public Health Genomics
Centers for Disease Control and Prevention
- 1:35 p.m. – 2:05 p.m. ACHDNC Efforts to Develop National Policy Recommendations for the
Retention and Use of Residual Dried Blood Spot Specimens after Newborn
Screening
R. Rodney Howell, M.D.
Chair, ACHDNC
- 2:05 p.m. – 2:15 p.m. Concluding Remarks – Dr. Teutsch
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