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

Nineteenth Meeting
June 11-12, 2009
Washington, D.C.

REVISED DRAFT AGENDA

Thursday, June 11, 2009

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

Genetics Education and Training

8:45 a.m. – 8:55 a.m. Genetics Education and Training Task Force Progress
Barbara Burns McGrath, R.N., Ph.D.
SACGHS Member

8:55 a.m. – 9:25 a.m. Progress of the Task Force Workgroups and Future Directions

8:55 – 9:05 Vence Bonham, Jr., J.D., Chair, Consumer and Patient Workgroup
9:05 – 9:15 Greg Feero, M.D., Ph.D. and David Dale, M.D., Chairs, Health Care
 Providers Workgroup
9:15 – 9:25 Kate Reed, M.P.H., Sc.M., C.G.C., Member of the Public Health
 Providers Workgroup

9:25 a.m. – 9:45 a.m. Committee Discussion

Public Comment Session

9:45 a.m. – 10:15 a.m. Public Comments

10:15 a.m. – 10:30 a.m. BREAK

Developments in Health Information Technology

10:30 a.m. – 10:50 a.m. Activities of the Office of the National Coordinator for Health Information
Technology Designed to Create a National Infrastructure
David Blumenthal, M.D., M.P.P.
National Coordinator for Health Information Technology
Department of Health and Human Services

10:50 – 11:00 Q & A

Genetics and the Future of the Health Care System

11:00 a.m. – 11:15 a.m.	Health Disparities and Changes Needed to Promote Health Equity Sarah Gehlert, Ph.D. Principal Investigator and Director of the University of Chicago’s Center for Interdisciplinary Health Disparities Research
11:15 – 11:25	Q&A
11:25 a.m. – 11:55 a.m.	Proposed Reforms in Health Care Delivery and Provider Payment Systems Michael Barr, M.D., M.B.A. Vice President, Practice Advocacy and Improvement American College of Physicians
11:55 – 12:05	Q&A
12:05 p.m. – 12:50 p.m.	LUNCH
12:50 p.m. – 1:05 p.m.	The Impact of Genomics on the Future of Oncology William G. Nelson, M.D., Ph.D. Chairman of Oncology and Director Sidney Kimmel Comprehensive Cancer Center Johns Hopkins University School of Medicine
1:05 p.m. – 1:20 p.m.	The Future of Genomics: a Pediatric Perspective Beth Pletcher, M.D. Associate Professor of Pediatrics Institute of Genomic Medicine, University of Medicine and Dentistry of New Jersey
1:20 – 1:30	Q&A
1:30 p.m. – 2:00 p.m.	Changes in Health Care from Patient Advocates’ Perspective Katie Hood, M.B.A. Chief Executive Officer The Michael J. Fox Foundation for Parkinson’s Research Myrl Weinberg, M.A. President National Health Council
2:00– 2:10	Q&A
2:10 p.m. – 2:30 p.m.	The Impact of Health Care System Changes on the Pharmaceutical and Diagnostics Industries Murray Aitken, M.B.A., M.Comm. Senior Vice President, Healthcare Insight IMS Health
2:30– 2:40	Q&A

- 2:40 p.m. – 2:55 p.m. BREAK
- 2:55 p.m. – 4:55 p.m. Committee Discussion on Important Issues and Next Steps in Genetics and the Future of the Health Care System

Gene Patents and Licensing Practices

- 4:55 p.m. – 5:10 p.m. Overview of Public Comments on the SACGHS Consultation Draft Report on Gene Patents and Licensing Practices and Their Impact on Patient Access to Genetic Tests
James P. Evans, M.D., Ph.D.
Chair, SACGHS Task Force on Gene Patents and Licensing Practices

- 5:10 p.m. – 5:15 p.m. Closing Remarks – Dr. Teutsch

Friday, June 12, 2009

- 8:30 a.m. – 8:35 a.m. Opening Remarks
Dr. Teutsch
SACGHS Chair

Direct-to-Consumer Genetic Testing

- 8:35 a.m. – 8:55 a.m. Presentation of Draft Report on Direct-to-Consumer Genetic Testing
Sylvia Au, M.S., CGC
SACGHS Member
- 8:55 a.m. – 9:25 a.m. Committee Discussion and Decisions Regarding Draft Report on Direct-to-Consumer Genomic Services

Clinical Utility and Comparative Effectiveness

- 9:25 a.m. – 9:45 a.m. Clinical Effectiveness, Clinical Utility, Comparative Effectiveness: An Evolving Landscape
Gurvaneet Randhawa, M.D., M.P.H.
Agency for Healthcare Research and Quality
- 9:45 – 9:55 Q&A
- 9:55 a.m. – 10:15 a.m. Future Directions and the Role of Genomics in Comparative Effectiveness
Harold Sox, M.D., M.A.C.P.
Chair
Institute of Medicine Committee on Comparative Effectiveness Research
Prioritization
- 10:15 – 10:25 Q&A

10:25 a.m. – 10:40 a.m.	BREAK
10:40 a.m. – 11:00 a.m.	Role of Genomics in Comparative Effectiveness Research, National Institute of Health Perspective Michael Lauer, M.D. Director, Division of Cardiovascular Sciences National Heart, Lung, and Blood Institute National Institutes of Health
11:00 – 10:10	Q&A
11:10 a.m. – 11:25 a.m.	Future Directions and Developments in Research Methodologies Steven Goodman, M.D., M.H.S., Ph.D. Professor of Oncology Sidney Kimmel Comprehensive Cancer Center Johns Hopkins University School of Medicine
11:25 – 11:40	Q&A
11:40 a.m. – 11:55 a.m.	Impact of Comparative Effectiveness Findings on Clinical Practice Marc Williams, M.D., SACGHS Member
11:55 – 12:10	Q&A
12:10 p.m. – 12:45 p.m.	Committee Discussion
12:45 p.m. – 1:30 p.m.	LUNCH

Federal Activities Related to Genetics/Genomics

1:30 p.m. – 1:50 p.m.	Report from the Centers for Medicare & Medicaid Services on Evidentiary Standards for Coverage Decisions on Genetic Tests Jeffrey Roche, M.D., MPH Medical Officer Division of Items and Devices Coverage & Analysis Group, Office of Clinical Standards and Quality Centers for Medicare & Medicaid Services
1:50 – 2:00	Q&A
2:00 p.m. – 2:20 p.m.	Updates Regarding Family History: Family History Tools and NIH's Upcoming State-of-the-Science Conference William (Greg) Feero, M.D., Ph.D. Senior Advisor to the Director for Genomic Medicine National Human Genome Research Institute
2:20 – 2:30	Q&A

2:30 p.m. – 2:45 p.m. Health IT and Standards to Support Clinical Research: Combining Clinical and Genomics Data
Rebecca Kush, Ph.D., Chairman and CEO, Clinical Data Interchange Standards Consortium (CDISC)
Jessica Nadler, Ph.D.
AAAS Science & Technology Policy Fellow
HHS Personalized Health Care Initiative

2:45 – 2:55 Q&A

Public Comment Session

2:55 p.m. – 3:25 p.m. Public Comments

3:25 p.m. – 3:30 p.m. Closing Remarks – Dr. Teutsch

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