

**Personalized Health Care Initiative Workshop:
“Understanding the Needs of Consumers in the Use of Genome-based
Health Information Services”**

AGENDA

12:30 – 12:45 pm Welcome, Meeting Objectives and Overview

Richard Campanelli, JD

*Counselor to the Secretary for Science and Public Health,
US Department of Health and Human Services*

12:45 – 1:05 pm Medical decision-making empowered by genomic information

Eric Topol, MD

*Director, Scripps Translational Science Institute
Dean, Scripps School of Medicine*

- How can validated genomic information empower consumers in medical decision-making?
- Compare and contrast what is currently available in the marketplace.
- What is your vision for the future genomic services?

1:05 – 1:30 pm Consumer interest in health and genomic information

Steve Bodhaine, MBA

Group President, Research/Product Development, Yankelovich

1:30 – 2:30 pm Panel 1: What is the consumer interest in genome-based health information?

1:30 – 2:10 pm

Panel Discussion

2:10 – 2:30 pm

Q&A

Linda Avey

Co-founder, 23andMe, Inc.

Esther Dyson

EDventure Holdings

Rebecca Fisher, MLIS

Patient Advocate

Matthew Holt

Co-founder Health 2.0 Conference

- What drives the consumer’s interest in health information for predicting health outcomes?
- What are key factors for motivating interest in genetic testing?
- For what information are consumers ready?

2:30 – 2:45 pm

Break

2:45 – 4:00 pm Panel 2: Is the testing process reliable, and is the information's privacy maintained?

2:45 – 3:25 pm Panel Discussion

3:25 – 4:00 pm Q&A

Deven McGraw, JD, MPH

Director, Health Privacy Project, Center for Democracy and Technology

Ryan Phelan

Founder and CEO, DNA Direct

Jeffrey Gulcher, MD, PhD

Chief Scientific Officer, deCODE genetics

Reed Tuckson, MD, FACP

Executive Vice President and Chief of Medical Affairs, UnitedHealth Group

- What are potential ways to inform consumers that quality control standards for testing are being met?
- How are risk assessments determined?
- Will (should) the genomic data be utilized for public health benefit or other population-based research in the future?
- Are there cautions that the consumer should consider when sharing their genomic information with others, such as family members, members of social network, or clinicians?
- What protections are currently or should be employed to protect the security and privacy of consumer genomic information?

4:00 – 5:15 pm Panel 3: what is currently useful to consumers, and what can they expect in the future?

4:00 – 4:50 pm Panel Discussion

4:50 – 5:15 pm Q&A

Mari Baker

President and CEO, Navigenics

Katherine Johansen, PhD

Senior Scientist, American Medical Association Program in Genetics and Molecular Medicine

Nancy Johnson

Senior Public Policy Advisor, Baker Donelson

Ronni Sandroff, MA

Director/Editor, Health and Family Information, Consumer Reports

Angela Trepanier MS, CGC

President, National Society of Genetic Counselors

Assistant Professor, Clinical Center for Molecular Medicine and Genetics, Wayne State University

- How can genomic information and explanatory resources deepen health literacy and support consumer empowerment for prevention?
- What checklist of resources or information should consumers have to assign value to genome-based health information services?
- How valuable is the information currently available relative to other health information, such as family history, blood pressure, BMI etc.?
- What can/should consumers expect in the future?

5:15 – 5:30 pm Looking to the future of consumer services (moderated discussion)

Michael Cowan, MD

Chief Medical Officer, BearingPoint