



Board on Health Sciences Policy

Roundtable on Translating Genomic-Based Research for Health

***Genomics-Enabled Learning Health Care Systems: Gathering and Using
Genomic Information to Improve Patient Care and Research
A Workshop***

December 8, 2014

**The Keck Center of the National Academies, Room 100
500 Fifth Street, NW
Washington, DC 20001**

MEETING OBJECTIVES

- TO EXPLORE HOW KEY PIECES OF GENETIC/GENOMIC INFORMATION CAN BE EFFECTIVELY AND EFFICIENTLY DELIVERED TO PATIENTS AND CLINICIANS FOR IMPROVING CARE.
- TO DISCUSS HOW BOTH THE HEALTH CARE SYSTEM AND GENOMIC DATA CAN BE USED FOR EVIDENCE GENERATION IN RESEARCH AND IN PATIENT CARE.
- TO ASSESS CURRENT BEST PRACTICES FOR USING KNOWLEDGE-GENERATING/LEARNING HEALTH CARE SYSTEMS AND WHICH MODELS MAY PROVIDE AN OPPORTUNITY FOR GENOMICS TO BE USED IN THE RAPID LEARNING PROCESS.

AGENDA

8:30–8:35 A.M.

Welcoming Remarks

Sharon F. Terry, *Roundtable Co-chair*
President and CEO
Genetic Alliance

Geoffrey Ginsburg, *Roundtable Co-chair*
Director, Center for Applied Genomics & Precision Medicine; Professor
of Medicine and Biomedical Engineering, Duke University

8:35–8:45 A.M.

Charge to workshop speakers and participants

Sam Shekar, *Workshop Co-chair*
Chief Medical Officer
Northrop Grumman Health IT

Geoffrey Ginsburg, *Workshop Co-chair*
Director, Center for Applied Genomics & Precision Medicine; Professor
of Medicine and Biomedical Engineering, Duke University

SESSION I: INTRODUCTION - OPPORTUNITIES FOR A LEARNING HEALTH CARE SYSTEM

Objectives: To understand the advantages of implementing a learning system, the potential economic incentives, and how genomic information may fit into this model.

8:45–9:05 A.M. Lynn Etheredge (confirmed)
Director
Rapid Learning Project

SESSION II: ADVANCING PATIENT CARE AND RESEARCH WITH GENOMIC INFORMATION

Objectives: To explore multiple sources of genomic data within the health care system and how it can be captured, accessed, and used as evidence for advancing patient care and research.

Moderator: Debra Leonard, University of Vermont College of Medicine

9:05–9:35 A.M. **Introduction: Ensuring Quality of Genomic Data**

Neil Risch (confirmed)
Professor, Division of Biostatistics
Director, Institute for Human Genetics
University of California, San Francisco;
Adjunct Investigator
Kaiser Permanente Division of Research

Josh Peterson (confirmed)
Assistant Professor of Biomedical Informatics, Assistant Professor of
Medicine; Director of Health Information, Technology Evaluation,
Vanderbilt University Medical Center

9:35–10:05 A.M. **Advancing Research**

Chris Chute (confirmed)
Section Head of Medical Informatics and
Professor of Medical Informatics
Mayo Clinic

Tom Fowler (confirmed)
Director of Public Health
Genomics England

10:05–10:20 A.M.	BREAK
10:20–10:50 A.M.	Advancing Patient Care
	Gail Jarvik (confirmed) Head and Professor, Division of Medical Genetics University of Washington School of Medicine
	Stephen Leffler (confirmed) Chief Medical Officer The University of Vermont Medical Center
10:50–11:45 A.M.	Discussion with Speakers and Attendees
	Neil Risch (confirmed) Josh Peterson (confirmed) Chris Chute (confirmed) Tom Fowler (confirmed) Gail Jarvik (confirmed) Stephen Leffler (confirmed)
11:45–12:35 P.M.	WORKING LUNCH

SESSION III: TRANSLATION OF GENOMICS FOR PATIENT CARE AND RESEARCH

Objectives: To examine how to build a knowledge-generating health care system for genomics and incentivize its use.

Moderator: Andrew Kasarskis, Icahn School of Medicine at Mount Sinai

12:35–1:35 P.M.	Knowledgeable Health Care System for Genomics
	Introduction/Overview

Chuck Friedman (confirmed)
Josiah Macy Jr. Professor of Medical Education
Chair, Department of Learning Health Sciences, Medical School
Professor of Information and Public Health
University of Michigan

Health System Data Research Perspective

Colin Hill (confirmed)

Chief Executive Officer, President, Chairman, and Co-Founder
GNS Healthcare

Health System Perspective

Alexander Ommaya (confirmed)

Senior Director, Clinical Effectiveness and Implementation Research
Association of American Medical Colleges

Fred Sanfilippo (confirmed)

Director, Healthcare Innovation Program
Emory University-Georgia Tech

1:35–2:35 P.M.

Clinical End User

Jason Vassy (confirmed)

Section of General Internal Medicine, VA Boston Healthcare System
Division of General Medicine, Brigham and Women's Hospital
Instructor, Harvard Medical School

Patient Perspective

Dixie Baker (confirmed)

Senior Partner
Martin, Blank & Associates

Commercial Developer Perspective

Scott Moss (confirmed)

Research Informatics Software Developer
Epic

Beyond the EHR

Ketan Paranjape (confirmed)

Director, Personalized Medicine
Intel

2:35–2:50 P.M.

BREAK

2:50–3:50 P.M.

Discussion with Speakers and Attendees

Chuck Friedman (confirmed)
Alexander Ommaya (confirmed)
Fred Sanfilippo (confirmed)
Jason Vassy (confirmed)
Dixie Baker (confirmed)
Scott Moss (confirmed)
Ketan Paranjape (confirmed)

Additional Discussant:

Sandy Aronson (confirmed)
Director of IT, Partners Healthcare Personalized Medicine

SESSION IV: INTEGRATING GENOMIC INFORMATION INTO THE EHR

Objectives: To examine ongoing efforts to develop a framework and guidance for how genomic information may effectively be integrated and used within the health care system workflow.

Moderator: Sam Shekar, Northrop Grumman Health IT

3:50–4:10 P.M.

Call to Action

Sandy Aronson (confirmed)
Director of IT
Partners Healthcare Personalized Medicine

John David Nolen (confirmed)
Managing Director, Laboratory Business Unit
Cerner Corporation

4:10–4:35 P.M.

Discussion with Speakers and Attendees

SESSION V: CONSIDERATIONS FOR THE FUTURE

What are the next steps for achieving effective integration of genomic data into the health care system for the short-term and long-term? What are the challenges associated with this incorporation and how can they be overcome to ensure that the information is fully utilized for improving patient care and research? Are there economic or other incentives for health care systems to invest in the knowledge-generating model?

Moderator: Geoffrey Ginsburg, Duke University

4:35–5:30 P.M.

Discussants

Lynn Etheredge (confirmed)
Tom Fowler (confirmed)
Chuck Friedman (confirmed)
Colin Hill (confirmed)
Stephen Leffler (confirmed)
John David Nolen (confirmed)
Sharon F. Terry (confirmed)

5:30–5:35 P.M.

SUMMARY AND CONCLUDING REMARKS

Sam Shekar, *Workshop Co-chair*
Chief Medical Officer
Northrop Grumman Health IT

Geoffrey Ginsburg, *Workshop Co-chair*
Director, Center for Applied Genomics & Precision Medicine; Professor
of Medicine and Biomedical Engineering, Duke University

5:35 P.M.

ADJOURN