



***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**

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**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.

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**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

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

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**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

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**SESSION II: ADVANCING PATIENT CARE AND RESEARCH WITH GENOMIC INFORMATION**

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**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**

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**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

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### **SESSION IV: INTEGRATING GENOMIC INFORMATION INTO THE EHR**

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**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**

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### **SESSION V: CONSIDERATIONS FOR THE FUTURE**

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**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**