Realizing the Potential of Genomics across the Continuum of Precision Health Care: A Workshop

October 12, 2022

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STATEMENT OF TASK

A planning committee of the National Academies of Sciences, Engineering, and Medicine will organize and conduct a public workshop to examine how genomic data are used in health care settings and to identify opportunities for advancement of precision health care delivery. The overarching goal of the workshop is to examine strategies to ensure that genomic applications are responsibly and equitably adopted to benefit populations as well as individuals over time.

The public workshop will feature invited presentations and discussions to explore:

- Examples of how genomic data are being used to assess health risk outside of traditional settings for clinical genetics (e.g., prenatal screening and testing, newborn screening, polygenic risk scores) and guide decision-making with an eye toward understanding challenges and opportunities related to equity of access to innovation in science, and population level adoption of genomic applications;
- How patients, clinicians, and payers assess and act upon the risks and benefits of genomic screening and diagnostic testing; and
- Challenges of integrating genomic data from various sources into clinical decision-making, including those obtained outside of traditional clinical care settings (e.g., direct-to-consumer, consumer directed, workplace genetic testing) to support equitable precision health care.

The planning committee will organize the workshop, develop the agenda, select and invite speakers and discussants, and moderate or identify moderators for the discussions. A broad array of stakeholders may take part in the workshop, including clinicians, genomics experts, users of the health care system (e.g., patients and families), payers, bioethicists, regulators, digital health experts, and policy makers. Proceedings of the presentations and discussions at the workshop will be prepared by a designated rapporteur in accordance with institutional guidelines.

WEDNESDAY, OCTOBER 12, 2022

SESSION I: Opening Remarks & Keynote

Moderator: Sarah Wordsworth, Professor and University Lecturer; Health Economics Research Centre, Nuffield Department of Population Health, University of Oxford

10:30 AM ET

Welcoming Remarks
Michelle Penny, *Roundtable Co-Chair*
Executive Vice President, Research & Development
Embark, Inc.

Greg Feero, *Roundtable Co-Chair*
Representing Journal of the American Medical Association
Professor, Department of Community and Family Medicine, Geisel School of Medicine
Faculty, Maine Dartmouth Family Medicine Residency Program

10:40–10:50 AM

Introduction and Charge to the Workshop Speakers and Participants
Mira Irons, *Workshop Planning Committee Co-Chair*
President & CEO
College of Physicians of Philadelphia

Christa Martin, *Workshop Planning Committee Co-Chair*
Chief Scientific Officer, Geisinger
Professor and Director, Autism & Developmental Medical Institute

10:50-11:15 AM

Keynote
Euan Ashley
Associate Dean, School of Medicine
Roger and Joelle Burnell Professor of Genomics and Precision Health
Professor of Medicine, Genetics, Biomedical Data Science, & Pathology
Stanford University

SESSION II: What Do Patients Need as Genomics Moves into Clinical Care?

Co-Moderators: Gwen Darien, Executive Vice President for Patient Advocacy and Engagement, National Patient Advocate Foundation and Candace Henley, Founder/Chief Surviving Officer, The Blue Hat Foundation

Objectives

- Explore how patients assess and act upon genetic risk information they receive from genomic applications that may change over time (e.g., consumer genetic testing, polygenic risk scores, prenatal testing).
- Examine what patients may need to make informed decisions surrounding genetic testing and follow up care.

11:15–11:30 AM

Keri Norris
Vice President of Health Equity, Diversity, and Inclusion
National Hemophilia Foundation

11:30–11:45 AM

Greta Goto
Founding Member
Prader-Willi Syndrome Alaska Parent Group
Co-Chair, Community Engagement in Genomics Working Group
NHGRI

11:45–12:00 PM

Cristi Radford
Product Director
Optum

12:00–12:25 PM

Panel Discussion

12:25-1:25 PM

Break

SESSION III: What Will it Take to Build an Equitable Precision Health Care System?

Moderator: Gabriel Lázaro-Muñoz, Assistant Professor of Psychiatry, Member of HMS Center for Bioethics, Harvard Medical School

Objectives

- Discuss what an equitable precision health care system is and what it would take to deliver on this promise for patients and clinicians.
- Explore barriers that could be broken down to build an equitable precision health care system (e.g. access to precision health tools and clinician effectiveness in using those tools)
- Examine opportunities for improving implementation by engaging underserved and diverse communities.

1:25–1:40 PM

Kellan Baker
Executive Director and Chief Learning Officer
Whitman-Walker Institute

1:40–1:55 PM

Consuelo Wilkins
Professor of Medicine
Senior Vice President and Senior Associate Dean, for Health Equity and Inclusive Excellence
Engagement Core Director, All of Us Research Program
Vanderbilt University Medical Center

1:55–2:10 PM

Mary Relling
Co-investigator and Co-Founder, Clinical Pharmacogenetics Implementation Consortium
Endowed Chair, Pharmaceutical Sciences Department
St. Jude Children's Research Hospital

2:10–2:35 PM

Panel Discussion

SESSION IV: What Genetic Testing Logistics Issues Need to be Addressed?

Moderator: Victoria Pratt, Vice President, Molecular Diagnostic Quality Assessments, Optum Genomics

Purpose

- Examine and compare what evidence (e.g., clinical validity and clinical utility) means in the context of insurance companies, the clinical setting, and laboratories creating genetic tests.
- Understand how patients, payers, and clinical providers assess the value and benefits of genomic screening and diagnostic testing.

2:35–2:50 PM ET

Lee Hilborne
Medical Director
Quest Diagnostics
Professor of Pathology and Laboratory Medicine
David Geffen School of Medicine
University of California, Los Angeles

2:50–3:05 PM

Mylynda Massart
Assistant Professor of Family Medicine
Department of Family Medicine
University of Pittsburgh
Founder and Director, UPMC Primary Care Precision Medicine Center
Chair of Family Medicine, UPMC Magee Women's Hospital

3:05–3:20 PM

Bruce Quinn
Principal
Bruce Quinn Associates LLC

3:20–3:45 PM **Panel Discussion**

3:45–4:05 PM **Break**

SESSION V: What are the System-level Challenges and Opportunities?

Moderator: W. Gregory Feero, Professor, Department of Community and Family Medicine, Geisel School of Medicine; Faculty, Maine Dartmouth Family Medicine Residency Program

Purpose

- Examine system-level barriers to widespread adoption of genomics and precision health care including data integration, cost and payment, and leadership buy-in.
- Discuss what non-geneticist clinicians may need in order to adopt genetic testing in clinical care.

4:05–4:25 PM ET **Initial Remarks (5 min. each)**

Philip Zazove
Professor Emeritus
Department of Family Medicine
University of Michigan

Tshaka Cunningham
Chief Scientific Officer and Co-founder
Polaris Genomics
Executive Director
Faith Based Genetic Research Institute

Karen Kaul
Chair, Department of Pathology and Laboratory Medicine
Duckworth Family Chair
NorthShore University HealthSystem
Clinical Professor of Pathology
University of Chicago Pritzker School of Medicine

Kara Maxwell
Assistant Professor of Medicine
Perelman School of Medicine
University of Pennsylvania

4:25–5:10 PM **Panel Discussion**

SESSION VI: What Will Genomics Adoption Look Like in the Future?

Moderator: Mira Irons, President & CEO, College of Physicians of Philadelphia

Purpose

- Explore what adoption may look like in the next 10-20 years – how clinicians will be ordering genetic testing, accessing and interpreting results, and using genetic data in routine healthcare. Explore how individuals will access their results and act on them as part of their healthcare.

5:10–5:35 PM

Moderated Discussion

Amy Compton-Phillips
President and Chief Clinical Officer
Press Ganey consulting division

David H. Ledbetter
Chief Clinical & Research Officer
Unified Patient Network, Inc.
Professor, Department of Psychiatry
University of Florida

5:35-5:50 PM

Wrap Up

Mira Irons, *Workshop Planning Committee Co-Chair*
President & CEO
College of Physicians of Philadelphia

Christa Martin, *Workshop Planning Committee Co-Chair*
Chief Scientific Officer, Geisinger
Professor and Director, Autism & Developmental Medical Institute