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About the Roundtable

The Roundtable on Genomics and Precision Health brings together leaders from government, academia, industry, foundations, associations, patient communities, and other stakeholder groups to meet and discuss global issues surrounding the translation of genomics and genetics research findings into medicine, public health, education, and policy. The primary purpose of the Roundtable is to foster dialogue across sectors and among interested parties and institutions, and to illuminate and scrutinize critical scientific and policy issues where Roundtable engagement and input will help further the field.

The Roundtable membership identifies scientific and policy issues where discussion and collaboration will help enable the translation of genomics into health care applications. Specific issues and agenda topics are determined by the Roundtable members, and span a broad range of areas relevant to the translation process. Current areas of emphasis include the discovery and development of precision therapeutics, clinical implementation of genomic medicine, health care disparities, health information technology and digital health, public health genomics, the use of genomic information for health care decision making, using genomic information and data science to generate knowledge for clinical practice and research, and education and ethical, legal, and social issues.

To achieve its objectives, the Roundtable conducts structured discussions, public workshops, and meetings, and enters into information-gathering activities, develops authored viewpoints and perspectives, organizes and supports collaboratives, and publishes workshop proceedings.
Working Groups & Areas of Interest

The Roundtable identifies interest areas that need highlighting and attention based on member areas of expertise and the evolution of the field of genomics and precision health. These groups are fluid in that they adapt to address challenges and areas of focus over time. The working groups for 2018-19 include:

**Precision Therapeutics**

The cost of developing new therapies has been on the rise, leading many pharmaceutical companies to examine innovative strategies to revitalize and create efficiencies in their drug discovery and development processes, including the adoption of genetically guided strategies to reduce attrition rates and increase the odds of success. Group members are considering patient engagement as a part of precision drug development efforts, education and awareness surrounding genetic resources, and entrepreneurial innovation that can accelerate drug development.

**Implementation**

With technological advances in gene sequencing driving down costs and a growing demonstration of utility for large-scale sequencing in disease diagnosis or to identify and monitor treatments for patients, an opportunity for more widespread use of genomic medicine in health care systems and the public health system has arisen. This group is exploring the impact on access to genetic testing as new technologies are introduced in health care settings as well as the role of employers in providing access to genomic and genetic services as part of health benefit packages.

**Digital Health**

This group is exploring the intersection between digital health technologies and genomic data by determining how the two fields can interface to enable precision health, improve research (patient reported outcomes, continuous phenotypes), and clinical care (monitoring, feedback, adherence). Other areas that may be explored by the group include strategies for successful digital health implementation in clinical care and privacy and regulatory challenges surrounding digital health applications. Overall, the group seeks to convene experts from the fields of genomics and digital health to illuminate areas of synergy and to inform each other about successes and challenges encountered in each sector.

**Overview**

The Overview group examines cross-cutting issues for all Roundtable members and working groups and responds to emerging issues within the genetics and genomics field. Currently, this group is focusing its efforts on disparities in access to genomic medicine.
Public Workshop

Understanding Disparities in Access to Genomic Medicine
A Workshop
JUNE 27, 2018

This workshop explored gaps in knowledge related to access to genomic medicine and discussed health care disparities and possible approaches to overcoming differential use of genomic medicine across populations. Model programs of care for diverse patient populations were highlighted. Participants discussed current challenges and possible best practices for alleviating health care disparities as they relate to genomics-based approaches.

Panelists at the Understanding Disparities in Access to Genomic Medicine workshop

Meetings

March 20, 2018

Roundtable members and speakers discussed some of the security challenges related to storing large-scale genomic data and opportunities for securing data by using emerging technologies like blockchain. The Roundtable also explored innovative collaborative models in the pre-competitive space that utilize genomic data to accelerate the development and use of precision medicine.

June 28, 2018

The Roundtable debriefed following the workshop on disparities in access to genomic medicine and discussed current precision medicine research initiatives including All of Us and efforts around shaping health systems at the World Economic Forum. The working groups also convened in breakout sessions to identify specific themes and challenges that could be explored in the upcoming year.

October 5, 2018

Roundtable members met virtually to discuss the recently released National Academies consensus report Returning Individual Research Results to Participants: Guidance for a New Research Paradigm. Members were debriefed on the recommendations from the committee as well as implications for genomic information by study staff and members of the consensus committee.

Prior to the workshop, several of the speakers, Roundtable members, and workshop registrants participated in a Twitter chat hosted by the National Academies’ Health and Medicine Division on the topics of #GenomicsDisparities. Topics discussed during the chat included challenges faced by patients when trying to access genetics-based services, opportunities for increasing access, the role of health systems and providers in improving access, and lessons that can be learned from other areas of medicine in how genetics-based services can be equitably provided.
Publications

Implementing and Evaluating Genomic Screening Programs in Health Care Systems
Proceedings of a Workshop
RELEASED: MARCH 16, 2018

Understanding Disparities in Access to Genomic Medicine
Proceedings of a Workshop
RELEASED: NOVEMBER 14, 2018

Perspectives

Accelerating Precision Health by Applying the Lessons Learned from Direct-to-Consumer Genomics to Digital Health Technologies
http://bit.ly/PrecisionHealthPerspective
POSTED: MARCH 19, 2018

A Proposed Approach for Implementing Genomics-Based Screening Programs for Healthy Adults
POSTED: DECEMBER 3, 2018

Perspectives, published by the National Academy of Medicine (NAM), are individually authored by Roundtable and Forum members and outside experts in health and health care. The views expressed in these papers are those of the authors and not necessarily of the authors’ organizations, the National Academy of Medicine (NAM), or the National Academies of Sciences, Engineering, and Medicine (the National Academies). Perspectives are intended to help inform and stimulate discussion. They are not reports of the NAM or the National Academies.
The Genomics and Population Health Action Collaborative (GPHAC) was initiated at the end of 2015 to explore opportunities for genomics research and applications to be used to improve health and prevent disease; inform and engage various stakeholders about the implementation of genomics in practice; and assess how evidence-based genomic applications could be integrated into implementation activities and programs at the health care-public health interface. GPHAC is currently organized into three working groups—population screening, cascade screening, and implementation. Together, these groups are assessing best practices and outcomes for implementation of population-level genomics activities; creating tools and educational materials to facilitate the uptake of genomics-based applications in health care and disease prevention; informing and engaging stakeholders; and exploring critical aspects of pilot projects for cascade screening/testing of at-risk relatives.

The Action Collaborative on Displaying and Integrating Genetic Information Through the EHR (DIGITizE), convenes key stakeholders from health information technology and management vendors, academic health centers, government agencies, and other organizations to work together to examine how genomic information can be uniformly represented and integrated into electronic health records in a standards-based format. An implementation guide containing the message structures and clinical decision support rules for a pharmacogenomics use case was finalized at the end of 2015 in preparation for pilot programs that began in 2016. Pilot participants include Intermountain Healthcare, Boston Children’s Hospital, Duke University, Johns Hopkins University, Mission Health, Partners Healthcare, St. Jude Children’s Research Hospital, University of Iowa, and University of Utah. Working groups explored additional use cases for further phases of the pilot projects in conjunction with a collaborative partner. In 2018, DIGITizE became part of the FHIR Foundation, whose goal is to provide support for the expansion of the FHIR community by promoting the global adoption and implementation of this platform.
Roundtable Membership (AS OF DECEMBER 2018)

Geoffrey S. Ginsburg, M.D., Ph.D. (Co-Chair)
Duke University

Michelle Penny, Ph.D. (Co-Chair)
Biogen

Naomi Aronson, Ph.D.
Blue Cross and Blue Shield Association

Aris Baras, M.B.A.
Regeneron Pharmaceuticals

John W. Belmont, M.D., Ph.D.
Illumina

Karina Bienfait, Ph.D.
Merck and Co., Inc.

Ann Cashion, Ph.D.
National Institute of Nursing Research

Robert B. Darnell, M.D., Ph.D.
The Rockefeller University

Joseph Donahue
Accenture

Katherine Donigan, Ph.D.
U.S. Food and Drug Administration

W. Gregory Feero, M.D., Ph.D.
JAMA

Marc Grodman, M.D.
Genosity

Jill Hagenkord, M.D.
Color Genomics

Emily Harris, Ph.D., M.P.H.
National Cancer Institute

Richard Hodes, M.D.
National Institute on Aging

Muin Khoury, M.D., Ph.D.
Centers for Disease Control and Prevention

Thomas Lehner, Ph.D., M.P.H.
National Institute of Mental Health

Sean McConnell, Ph.D.
American Medical Association

Jennifer Moser, Ph.D.
Department of Veterans Affairs

Anna Pettersson, Ph.D.
Pfizer Inc.

Victoria M. Pratt, Ph.D., FACMG
Association for Molecular Pathology

Laura Lyman Rodriguez, Ph.D.
National Human Genome Research Institute

Nadeem Sarwar, Ph.D.
Eisai Inc.

Sheri Schully, Ph.D.
NIH Office of Disease Prevention

Joan A. Scott, M.S., C.G.C.
Health Resources and Services Administration

Sam Shekar, M.D., M.P.H.
Northrop Grumman Information Systems

Nikoletta Sidiropoulos, M.D.
The University of Vermont Medical Center and The University of Vermont Health Network Medical Group

Katherine Johansen Taber, Ph.D.
Counsyl, Inc.

Sharon F. Terry, M.A.
Genetic Alliance

Joyce Tung, Ph.D.
23andMe

Jameson Voss, M.D., M.P.H.
Air Force Medical Support Agency

Michael S. Watson, Ph.D.
American College of Medical Genetics and Genomics

Karen E. Weck, M.D., FCAP
College of American Pathologists

Catherine A. Wicklund, M.S., C.G.C.
National Society of Genetic Counselors

Benjamin Wiegand, Ph.D.
Johnson & Johnson

Huntington F. Willard, Ph.D.
Geisinger National Precision Health

Janet K. Williams, Ph.D., R.N., FAAN
American Academy of Nursing
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United States Air Force Medical Service
The University of Vermont Medical Center and The University of Vermont Health Network Medical Group

Associations, nonprofits, and health systems 32%
Industry 39%
Government 29%

ROUND TABLE SPONSOR REPRESENTATION
### Roundtable Timeline

#### 2007
- **July 11−12**: Meeting 1
- **December 4**: Diffusion and Use of Genomic Innovations in Health and Medicine Workshop
- **December 5**: Meeting 2

#### 2008
- **April 1−2**: Meeting 3
- **July 28**: Innovations in Service Delivery in the Age of Genomics Workshop
- **July 29**: Meeting 4
- **October 6−7**: Meeting 5

#### 2009
- **February 12**: Systems for Research and Evaluation for Translating Genome-Based Discoveries for Health Workshop
- **February 13**: Meeting 6
- **June 9−11**: Meeting 7
- **August 31-September 1**: Direct-to-Consumer Genetic Testing Workshop
- **November 16−17**: Meeting 8

#### 2010
- **March 22**: The Value of Genetic and Genomic Technologies Workshop
- **March 23**: Meeting 9
- **May 24**: Challenges and Opportunities in Using Newborn Screening Samples for Translational Research Workshop; Meeting 10
- **July 22**: Establishing Precompetitive Collaborations to Stimulate Genomics-Driven Drug Development Workshop
- **July 23**: Meeting 11
- **November 17**: Generating Evidence for Genomic Diagnostic Test Development Workshop
- **November 16−17**: Meeting 12

#### 2011
- **February 22−23**: Meeting 13
- **July 19**: Integrating Large-Scale Genomic Information into Clinical Practice Workshop
- **July 20**: Meeting 14
- **November 15**: Facilitating Development and Utilization of Genome-Based Diagnostic Technologies Workshop
- **November 16**: Meeting 15

#### 2012
- **March 21**: New Paradigms in Drug Discovery: How Genomic Data Are Being Used to Revolutionize the Drug Discovery and Development Process Workshop
- **March 22**: Meeting 16
- **May 24**: Evidence for Clinical Utility of Molecular Diagnostics in Oncology Workshop
- **July 17−18**: Assessing the Economics of Genomic Medicine Workshop
- **July 18**: Meeting 17
- **October 4−5**: Sharing Clinical Research Data Workshop
- **December 3**: Improving the Efficiency and Effectiveness of Genomic Science Translation Workshop
- **December 4**: Meeting 18

#### 2013
- **February 27**: Refining Processes for the Co-Development of Genome-Based Therapeutics and Companion Diagnostic Tests Workshop
- **February 28**: Meeting 19
- **June 5**: Conflict of Interest and Medical Innovation: Ensuring Integrity While Facilitating Innovation in Medical Research Workshop
- **June 24**: Genomics-Enabled Drug Repositioning and Drug Repurposing Workshop
- **June 25**: Meeting 20
- **December 4−5**: Meeting 21

#### 2014
- **February 3**: Assessing Genomic Sequencing Information for Health Care Decision Making Workshop
- **February 4**: Meeting 22
- **August 18**: Improving Genetics Education in Graduate and Continuing Health Professional Education Workshop
- **August 19**: Meeting 23

#### 2015
- **March 10−11**: Meeting 25
- **July 14−15**: Meeting 26
- **November 19**: Applying an Implementation Science Approach to Genomic Medicine Workshop
- **November 20**: Meeting 27

#### 2016
- **March 22**: Deriving Drug Discovery Value from Large-Scale Genetic Bioresources Workshop
- **March 23**: Meeting 28
- **July 19−20**: Meeting 29
- **November 9**: Meeting 30

#### 2017
- **March 8**: Enabling Precision Medicine: The Role of Genetics in Clinical Drug Development Workshop
- **March 9**: Meeting 31
- **July 17−18**: Meeting 32
- **November 1**: Implementing and Evaluating Genomic Screening Programs in Health Care Systems Workshop
- **November 2**: Meeting 33

#### 2018
- **March 20**: Meeting 34
- **June 27**: Understanding Disparities in Access to Genomic Medicine Workshop
- **June 28**: Meeting 35
- **October 5**: Virtual Meeting on Return of Research Results

#### 2019
- **January 23-24**: Meeting with Keystone Symposia and American College of Cardiology
- **March 27-28**: Meeting 36
- **June 25-26**: Meeting 37
- **October 29-30**: Meeting 38
ABOUT THE NATIONAL ACADEMIES

The National Academy of Sciences, National Academy of Engineering, and National Academy of Medicine work together as the National Academies of Sciences, Engineering, and Medicine (“the Academies”) to provide independent, objective analysis and advice to the nation and conduct other activities to solve complex problems and inform public policy decisions. The Academies also encourage education and research, recognize outstanding contributions to knowledge, and increase public understanding in matters of science, engineering, and medicine.

The Health and Medicine Division (HMD), formerly known as the program unit of the Institute of Medicine, is a division of the Academies. HMD’s aim is to help those in government and the private sector make informed health decisions by providing evidence upon which they can rely. Each year, more than 3,000 individuals volunteer their time, knowledge, and expertise to advance the nation’s health through the work of HMD.

Many of the studies that HMD undertakes are requested by federal agencies and independent organizations; others begin as specific mandates from Congress. While our expert, consensus committees are vital to our advisory role, HMD also convenes a series of forums, roundtables, and standing committees, as well as other activities, to facilitate discussion; discovery; and critical, cross-disciplinary thinking.
To learn more about the Roundtable, visit nationalacademies.org/GenomicsRT