The National Academies of SCIENCES ENGINEERING MEDICINE

Roundtable on GENOMICS AND PRECISION HEALTH

2019 ANNUAL REPORT

Contents

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.

nationalacademies.org/our-work/roundtable-on-genomics-and-precision-health

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 2019-20 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 and multisector collaborations 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 integration of consumer genomics with clinical care.

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 of interest include identifying strategies for successful digital health implementation in clinical care, privacy and regulatory challenges surrounding digital health applications, and utilizing digital health technologies to improve drug development.

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 participant engagement to enable precision health.

In 2020, the Roundatable on Genomics and Precision Health will undergo a formal strategic planning process to develop area of focus for 2021 and beyond.

Public Workshop

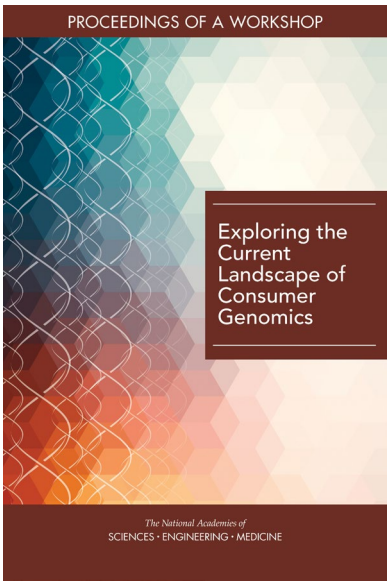
Exploring the Current Landscape of Consumer Genomics

A Workshop

OCTOBER 29, 2019

Click **here** to learn more about the workshop.

This workshop looked at the current landscape of consumer genomics and implications for how genetic test information is used or may be used in research and clinical care. Discussions at the workshop focused on understanding how consumers use consumer genomics testing, integration within scientific and medical communities, diversity of genetic databases and the implications for health disparities, and regulatory and health policy issues.



The publication of the proceedings can be found **here**

Meetings

January 21-25, 2019

A group of Roundtable members attended the Keystone Symposia on Digital Health: From Science to Application to discuss issues pertaining to precision health and digital health. The Roundtable's Digital Health interest group co-developed a session for the Keystone meeting with the American College of Cardiology focusing on strategies for digital health implementation and some of the challenges encountered in the field. Roundtable members and invited speakers convened on January 23 for a member discussion focusing on critical policy issues for digital health and genomics and future directions that the Roundtable could take in the digital health space.

March 27, 2019

Roundtable members and several speakers from the Roundtable on Population Health and Health Improvement discussed issues at the interface of population health and genomics. Other topics explored during the meeting included privacy and regulatory challenges associated with digital health applications and how employers can play a role in providing access to genomic medicine.

June 25-26, 2019

Roundtable members discussed the participant technology strategy of the All of Us Program and visited Vibrent Health, an organization working on the technology aspect of participant engagement and retention. The following day's agenda included discussions around participant engagement for precision therapeutics and health literacy considerations for genomic medicine.

October 30, 2019

The Roundtable debriefed following its public workshop on consumer genomics and heard from invited speakers on current legislation pertaining to precision health and access to genetic testing. Members also discussed engagement and attitudes surrounding clinical trial participation and had an opportunity to meet with their working groups to identify next steps and follow-up activities.

Action Collaboratives

The following action collaboratives are ad hoc activities under the auspices of the Roundtable on Genomics and Precision Health at the National Academies of Sciences, Engineering, and Medicine (the National Academies). Products produced by an action collaborative do not necessarily represent the views of any one organization, the Roundtable, or the National Academies and have not been subjected to the review procedures of, nor are they a report or product of, the National Academies.

Genomics and Population Health Action Collaborative (GPHAC)

click **here** to learn more about the collaborative

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 participants met on March 28, 2019 for a meeting focused on developing implementation strategies and resources for cascade and population screening for Hereditary Breast and Ovarian Cancer, Lynch syndrome, and Familial Hypercholesterolemia. Stakeholders from the implementation science, patient advocacy, and genomics research communities participated in the meeting. During and after the meeting, participants discussed potential activities and next steps for the collaborative as it reaches the final year.

GPHAC participants gathered for a photo after the meeting on March 28, 2019. The meeting focused on developing strategies and resources for cascade and population screening for identified health issues.

Learn more about former action collaboratives hosted by the Genomics Roundtable by clicking below:

Global Genomic Medicine Collaborative (G2MC)

DIGITizE: Displaying and Integrating Genetic Information Through the EHR Action Collaborative

Roundtable Membership (AS OF DECEMBER 2019)

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

Michelle Penny, Ph.D. (Co-Chair)
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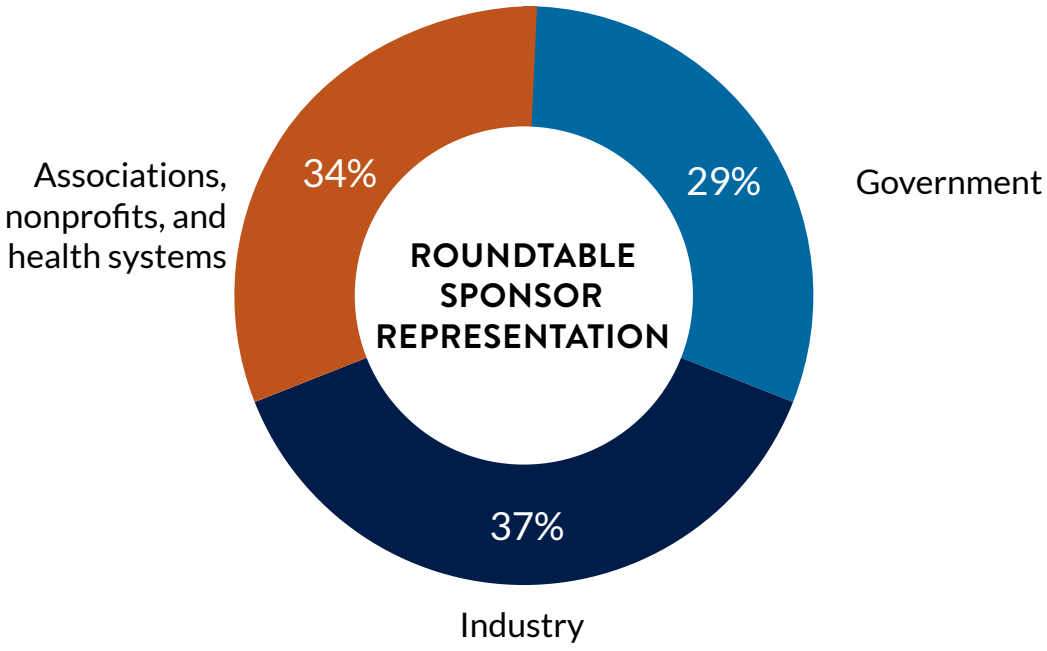
Vibrent Health



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 18: 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 Repurposing and Repositioning 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

December 8: Genomics-Enabled Learning Health Care Systems: Gathering and Using Genomic Information to Improve Patient Care and Research Workshop

December 9: Meeting 24

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: Exploring the Current Landscape of Consumer Genomics Workshop

October 30: Meeting 38

2020

March 24: The Role of Digital Health Technologies in Drug Development Workshop

March 25: Meeting 39

June 22-23: Meeting 40 (strategic planning)

November 10-11: Meeting 41 (strategic planning)

Roundtable Staff

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