NATIONAL ACADEMIES Sciences Engineering Medicine

Board on Health Sciences Policy

Roundtable on Genomics and Precision Health

Strategic Plan Reflection on the Roundtable's Work since 2020 and a Look Ahead

November 15, 2023

Public Webcast Access Link:

November 15, 2023 (12-1:15 PM ET):
https://www.nationalacademies.org/event/40968_11-2023_roundtable-on-genomics-and-precision-health-strategic-plan-reflection-on-the-roundtables-work-since-2020

NATIONAL ACADEMIES *Sciences Engineering Medicine*

Board on Health Sciences Policy

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November 15, 2023

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AGENDA

Strategic Plan Reflection on the Roundtable's Work Since 2020 and a Look Ahead

Public Webcast: November 15, 2023

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STRATEGIC PLAN REFLECTION ON THE ROUNDTABLE'S WORK SINCE 2020 AND A LOOK AHEAD

12:00 – 12:05 PM

Welcome and Overview of the Roundtable

W. Gregory (Greg) Feero, *Roundtable Co-chair*
Representing Journal of American Medical Association
Professor, Department of Community and Family Medicine
Geisel School of Medicine
Faculty
Maine Dartmouth Family Medicine Residency Program

Catherine (Cathy) Wicklund, *Roundtable Co-chair*
Representing National Society of Genetic Counselors
Senior Manager and Medical Science Liaison, Clinical Strategy Lead
Myriad Genetics
Adjunct Professor of Obstetrics and Gynecology (Clinical Genetics)
Feinberg School of Medicine, Center for Genetic Medicine
Northwestern University

12:05 – 12:15 PM

Improving Diversity of the Genomics Workforce

Chazeman Jackson, *Workshop Co-chair*
Senior Director, Diversity Equity and Inclusion
American Society of Human Genetics

Katie Johansen Taber, *Workshop Co-chair*
Vice President, Clinical Product Research & Partnerships
Myriad Genetics

12:15 – 12:25 PM

Views & Voices: Reporting Genetics and Genomics

Michelle Penny, *Shaping the Dialogue Working Group Member*
Executive Vice President, Research & Development
Embark Inc.

12:25 – 12:35 PM

Realizing the Potential of Genomics across the Continuum of Precision Health Care

Christa Martin, *Workshop Co-chair*
Chief Scientific Officer
Professor and Director
Autism & Developmental Medicine Institute
Geisinger

12:35 – 12:45 PM

Next-Generation Screening – The Promise and Perils of DNA Sequencing of Newborns at Birth

Natasha Bonhomme, *Workshop Co-chair*
Founder
Expecting Health
Chief Strategy Officer
Genetic Alliance

Catherine Wicklund, *Workshop Co-chair*
Representing National Society of Genetic Counselors
Senior Manager and Medical Science Liaison, Clinical Strategy Lead
Myriad Genetics
Adjunct Professor of Obstetrics and Gynecology (Clinical Genetics)
Feinberg School of Medicine, Center for Genetic Medicine
Northwestern University

12:45 – 1:10 PM

Discussion

Moderated by:
Ryan Taft, *Innovation Working Group Co-Lead*
Vice President, Scientific Research
Illumina, Inc.

1:10 – 1:15 PM

Wrap-up, adjourn

W. Gregory Feero, *Roundtable Co-chair*

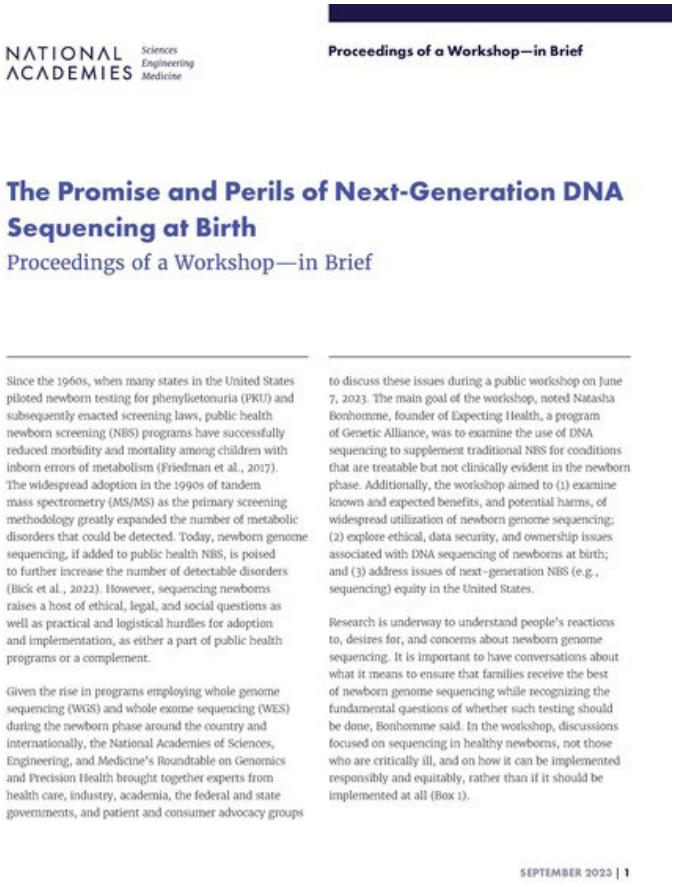
ANNOUNCEMENTS

NATIONAL ACADEMIES *Sciences Engineering Medicine*

New Proceedings in Brief of a Workshop and Infographic!

The Promise and Perils of Next-Generation DNA Sequencing at Birth

Link: https://doi.org/10.17226/27243



NATIONAL ACADEMIES *Sciences Engineering Medicine*

Proceedings of a Workshop—in Brief

The Promise and Perils of Next-Generation DNA Sequencing at Birth

Proceedings of a Workshop—in Brief

Since the 1960s, when many states in the United States piloted newborn testing for phenylketonuria (PKU) and subsequently enacted screening laws, public health newborn screening (NBS) programs have successfully reduced morbidity and mortality among children with inborn errors of metabolism (Friedman et al., 2017). The widespread adoption in the 1990s of tandem mass spectrometry (MS/MS) as the primary screening methodology greatly expanded the number of metabolic disorders that could be detected. Today, newborn genome sequencing, if added to public health NBS, is poised to further increase the number of detectable disorders (Bick et al., 2022). However, sequencing newborns raises a host of ethical, legal, and social questions as well as practical and logistical hurdles for adoption and implementation, as either a part of public health programs or a complement.

Given the rise in programs employing whole genome sequencing (WGS) and whole exome sequencing (WES) during the newborn phase around the country and internationally, the National Academies of Sciences, Engineering, and Medicine's Roundtable on Genomics and Precision Health brought together experts from health care, industry, academia, the federal and state governments, and patient and consumer advocacy groups to discuss these issues during a public workshop on June 7, 2023. The main goal of the workshop, noted Natasha Bonhomme, founder of Expecting Health, a program of Genetic Alliance, was to examine the use of DNA sequencing to supplement traditional NBS for conditions that are treatable but not clinically evident in the newborn phase. Additionally, the workshop aimed to (1) examine known and expected benefits, and potential harms, of widespread utilization of newborn genome sequencing; (2) explore ethical, data security, and ownership issues associated with DNA sequencing of newborns at birth; and (3) address issues of next-generation NBS (e.g., sequencing) equity in the United States.

Research is underway to understand people's reactions to, desires for, and concerns about newborn genome sequencing. It is important to have conversations about what it means to ensure that families receive the best of newborn genome sequencing while recognizing the fundamental questions of whether such testing should be done, Bonhomme said. In the workshop, discussions focused on sequencing in healthy newborns, not those who are critically ill, and on how it can be implemented responsibly and equitably, rather than if it should be implemented at all (Box 1).

SEPTEMBER 2023 | 1

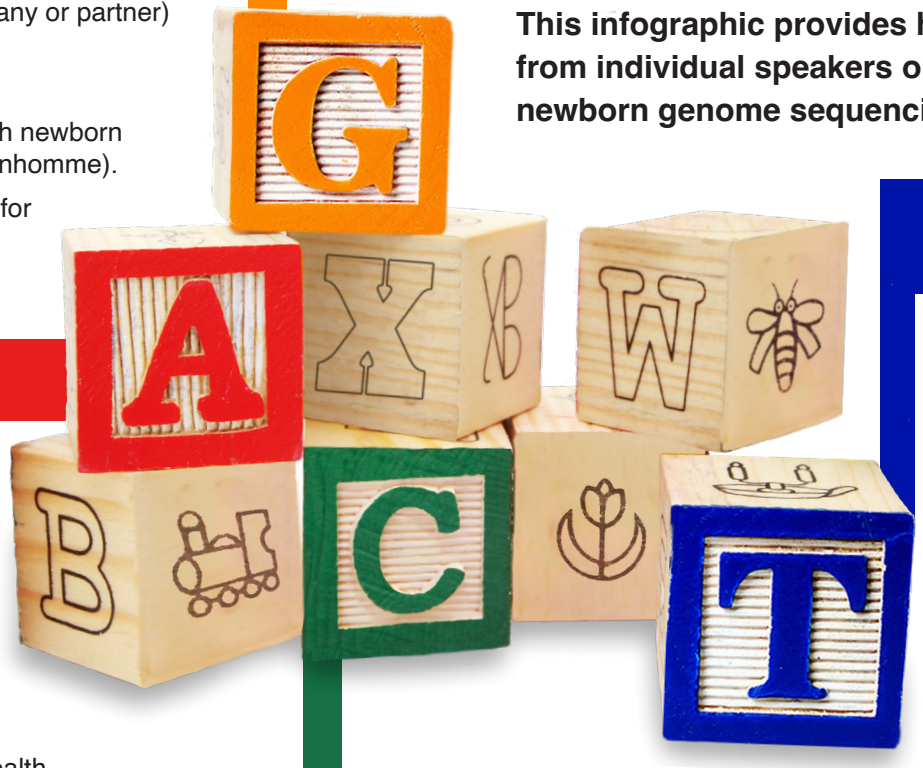
The Promise and Perils of Next-Generation DNA Sequencing at Birth

The National Academies of Sciences, Engineering, and Medicine convened a workshop to examine the use of DNA sequencing to supplement traditional newborn screening for conditions that are treatable but not clinically evident in the newborn phase. This infographic provides high-level takeaways from individual speakers on considerations for newborn genome sequencing.

What pathways exist for newborn genetic sequencing?

- **Clinical** (e.g., in the NICU) (Goldenberg).
- **Direct through health care providers** (e.g., providers ordering a test from an outside company or partner) (Goldenberg).
- **Direct to consumers** (Goldenberg).
- **Supplemental** to current public health newborn screening, but not a replacement (Bonhomme).

Each of these pathways has implications for **consent, returning results, follow-up** (Goldenberg), and **cost** (Veenstra).



What are some of the benefits and harms to consider?

- **Making sequencing more available** can increase early identification, provide families valuable information, and limit diagnostic odyssey (Hu).
- **Accessible follow-up care** is important for reducing burdens to families, **increasing equity,** and using improved health outcomes as measures of success (Hu, Woolford).
- Sequencing could increase preexisting health system inequities; therefore, it is important to **consider intersecting health disparities** (Goldenberg).

What are some of the policy and regulatory implications to consider?

- Regulatory considerations include **protecting privacy,** addressing concerns about **data security,** and ensuring **ethical data stewardship** (Grant, Peay, Powell).
- Widespread sequencing raises concerns about **improper use of DNA data,** including possible misuse by law enforcement (Grant).

How does sequencing affect communities, and how can community members be involved?

- **More voices are needed at the table** for successful implementation of newborn DNA sequencing (Fletcher, Hu, Klein).
- Perspectives are needed from **people living with genetic disorders** (Woolford), their **families** (Hu), and **groups who have been underrepresented in genomics research and minoritized in health care** (Bonhomme, Fletcher, Goldenberg).

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New Consensus Study!

Newborn Screening: Current Landscape and Future Directions

The National Academies is seeking suggestions for experts to participate in a new study, "Newborn Screening: Current Landscape and Future Directions." The resulting committee of experts will conduct a study to examine the current landscape of newborn screening (NBS) systems, processes, and research in the U.S. and consider sustainable adoption of screening for new conditions using new technologies. The report will provide both short-term options to strengthen existing NBS programs and establish a vision for the next 5-15 years.

12-15 volunteer experts are needed to serve on the committee, in addition to collecting information for potential speakers, participants, and peer reviewers for any publications resulting from the activity.

Expertise in the following areas is desired:

- Public health screening at the state and/or federal levels, including recommended uniform screening panel (RUSP) review
- Patient and family lived experience
- Clinical care, including screening, return of results, and follow up care
- Existing and emerging technologies for newborn screening
- Clinical lab practice
- Bioethics including privacy, legal, and equity in access issues
- Data collection, sharing, and use
- Health economics, coverage, and reimbursement

Please submit nominations by **November 17, 2023** using the link below:

https://survey.alchemer.com/s3/7583063/HMD-HSP-Newborn-Screening-Current-Landscape-and-Future-Directions

GENOMICS ROUNDTABLE INFORMATION

NATIONAL ACADEMIES Sciences Engineering Medicine

Roundtable on GENOMICS and PRECISION HEALTH

The sequencing of the human genome is rapidly opening new doors to research and progress in biology, medicine, and health care. At the same time, these developments have produced a diversity of new issues to be addressed.

The National Academies of Sciences, Engineering, and Medicine has convened a Roundtable on Genomics and Precision Health (previously the Roundtable on Translating Genomic-Based Research for Health) that brings together leaders from academia, industry, government, foundations and associations, and representatives of patient and consumer interests who have a mutual concern and interest in addressing the issues surrounding the translation of genome-based research for use in maintaining and improving health. The mission of the Roundtable is to advance the field of genomics and improve the translation of research findings to health care, education, and policy. The Roundtable will discuss the translation process, identify challenges at various points in the process, and discuss approaches to address those challenges.

The field of genomics and its translation involves many disciplines, and takes place within different economic, social, and cultural contexts, necessitating a need for increased communication and understanding across these fields. As a convening mechanism for interested parties from diverse perspectives to meet and discuss complex issues of mutual concern in a neutral setting, the Roundtable: fosters dialogue across sectors and institutions; illuminates issues, but does not necessarily resolve them; and fosters collaboration among interested parties.

To achieve its objectives, the Roundtable conducts structured discussions, workshops, and symposia. Workshop summaries will be published and collaborative efforts among members are encouraged (e.g., journal articles). Specific issues and agenda topics are determined by the Roundtable membership, and span a broad range of issues relevant to the translation process.

Issues may include the integration and coordination of genomic information into health care and public health including encompassing standards for genetic screening and testing, improving information technology for use in clinical decision making, ensuring access while protecting privacy, and using genomic information to reduce health disparities. The patient and family perspective on the use of genomic information for translation includes social and behavioral issues for target populations. There are evolving requirements for the health professional community, and the need to be able to understand and responsibly apply genomics to medicine and public health.

Of increasing importance is the need to identify the economic implications of using genome-based research for health. Such issues include incentives, cost-effectiveness, and sustainability.

Issues related to the developing science base are also important in the translation process. Such issues could include studies of gene-environment interactions, as well as the implications of genomics for complex disorders such as addiction, mental illness, and chronic diseases.

Roundtable sponsors include federal agencies, pharmaceutical companies, medical and scientific associations, foundations, and patient/public representatives. For more information about the Roundtable on Genomics and Precision Health, please visit our website at nationalacademies.org/GenomicsRT or contact Sarah Beachy at 202-334-2217, or by e-mail at sbeachy@nas.edu.

500 Fifth Street, NW, Washington, DC 20001
Phone 202.334.2217 E-mail sbeachy@nas.edu nationalacademies.org/GenomicsRT

Roundtable on Genomics and Precision Health Membership

W. Gregory Feero, M.D., Ph.D. (Co-Chair) *JAMA*
Catherine A. Wicklund, M.S., CGC (Co-Chair) National Society of Genetic Counselors

Devin Absher, Ph.D.
Kaiser Foundation Health Plan, Inc.

Naomi Aronson, Ph.D.
BlueCross/BlueShield Association

Aris Baras, M.D., M.B.A.
Regeneron Pharmaceuticals

Vence Bonham, Jr., J.D.
National Human Genome Research Institute

Jeffrey P. Brosco, M.D., Ph.D.
Health Resources and Services Administration

Bernice Coleman, Ph.D., ACNP-BC, FAHA, FAAN
American Academy of Nursing

Robert B. Darnell, M.D., Ph.D.
The Rockefeller University / NY Genome Center

Jennifer Goldsack, M.Chem, M.A., M.B.A.
Digital Medicine Society (DiMe)

Geoff Hollett, Ph.D.
American Medical Association

Mira Irons, M.D., FACMG
College of Physicians of Philadelphia

Praduman Jain, M.S.
Vibrent Health

Katherine Johansen Taber, Ph.D.
Myriad Women's Health

Sekar Kathiresan, M.D.
Massachusetts General Hospital

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

Susan Klugman, M.D.
American College of Medical Genetics and Genomics

Bruce Korf, Ph.D.
Global Genomic Medicine Collaborative (G2MC)

Charles Lee, Ph.D., FACMG
The Jackson Laboratory for Genomic Medicine

Christa Lese Martin, Ph.D., FACMG
Geisinger

Molly McGinniss, M.S., CGC
Genome Medical, Inc.

Mona Miller, M.P.P.
American Society of Human Genetics

Adele Mitchell, Ph.D.
Biogen

Jennifer Moser, Ph.D.
U.S. Department of Veterans Affairs

Kenneth Offit, M.D.
American Society of Clinical Oncology

Michelle Penny, Ph.D.
Embark, Inc.

Kathryn A. Phillips, Ph.D.
University of California, San Francisco

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

Nalini Raghavachi, Ph.D.
National Institute on Aging

Sheri Schully, Ph.D.
All of Us Research Program, NIH

Geetha Senthil, Ph.D.
National Institute of Mental Health

Anil Shanker, Ph.D.
Meharry Medical College

Nonniekaye Shelburne, CRNP, M.S., AOCN
National Cancer Institute

Ryan Taft, Ph.D.
Illumina. Inc.

Jacquelyn Taylor, Ph.D.
Columbia University School of Nursing

Sharon Terry, M.A.
Genetic Alliance

Joyce Tung, Ph.D.
23andMe, Inc.

Thierry Vilboux, Ph.D.
U.S. Food and Drug Administration

Jameson D. Voss, M.D., M.P.H., FACPM
U.S. Air Force

Karen Weck, M.D.
College of American Pathologists

Robert S. Wildin, M.D.
University of Vermont Health Network

Sarah Wordsworth, Ph.D.
University of Oxford

National Academy of Medicine Fellow
Paule Joseph, Ph.D., M.S., FNP-BC, FAAN
Inaugural American Academy of Nursing Fellow at NAM

Project Staff
Sarah H. Beachy, Ph.D., *Roundtable Director*
Kathryn Asalone, Ph.D., *Associate Program Officer*
Samantha Schumm, Ph.D., *Program Officer*
Lydia Teferra, *Research Associate*
Ashley Pitt, *Senior Program Assistant*

VISION	**Realizing the full potential of health for all through genomics and precision health.**
MISSION	**We bring together diverse voices to encourage innovation and actions that foster the wide adoption of and equitable access to the benefits of genomics and precision health.**

As a group of committed parties, we believe in…

- Creating an inclusive and optimistic environment for discussion
- Learning from successes and missteps in the field
- Demanding reproducible evidence-based science
- Sharing trustworthy information
- Embracing interdisciplinary strategies
- Optimizing data privacy and security
- Advancing health equity in all that we do

The Roundtable focuses its energy and resources on these priorities:

DRIVE **INNOVATION** IN GENOMICS AND PRECISION HEALTH	Identify the competing barriers and facilitators of innovation for genomics-based diagnostics, risk assessment tools, and therapies. Leverage opportunities to learn from and promote innovative approaches that can accelerate commercialization and integration to drive impact of genomics on precision health.
SPUR THE **ADOPTION** OF GENOMICS-BASED TOOLS AND PRECISION HEALTH APPROACHES	Cultivate evidence-based practices across the health care and public health systems for adopting genomics and precision health. Draw attention to gaps in adoption and their root causes and highlight potential solutions.
ACHIEVE **EQUITY** IN GENOMICS AND PRECISION HEALTH	Foster action related to underrepresentation and inequities in genomic research, workforce, and access to genomic services by people who need them. Look internally to improve the processes and practices the Roundtable employs to achieve its mission.
SHAPE THE **POLICY DIALOGUE** ABOUT GENOMICS AND PRECISION HEALTH	Accelerate the dissemination of actionable knowledge to shape practice and increase public awareness. Inform and influence how decisions are made.

DEFINITIONS

Precision Health | Inclusive of precision medicine, precision health is a broader, proactive and people-focused approach to health, relying on individual-focused care and everyday decision-making to better predict, prevent, and treat disease.

Genetics | Study of heredity, genes, and genetic variation.

Genomics | Study of the genome by using DNA sequencing and other technologies to understand gene structure, function, and regulation.

PUBLIC WEBCAST INFORMATION

NATIONAL ACADEMIES Sciences Engineering Medicine

Board on Health Sciences Policy *Roundtable on Genomics and Precision Health*

Strategic Plan Reflection on the Roundtable's Work since 2020

November 15, 2023

Speaker Biographies

Natasha Bonhomme, is the Founder of Expecting Health and has over 15 years of nonprofit and maternal and child health experience. She launched Expecting Health to bring a range of family, community, and professional stakeholders together to address the need for clearer information, high quality engagement, and scalable solutions in healthcare. Her focus is on centering families' perspectives into policy and program design and implementation. Natasha led and managed an extensive study of women (with more than 2,000 expectant and new mothers) to understand their attitudes towards newborn screening and their preferences on how and when to be educated. She created and oversees Baby's First Test a national resource center which reaches over 600,000 families and health providers annually. As director of Baby's First Test, Natasha has testified before the US Senate Health, Education, Labor, and Pension Committee's Subcommittee on Children and Families on the importance of public education on screening. She sits on numerous committees on maternal and child health including the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children. Outside of the office, Natasha has been involved in numerous community-based initiatives and currently is a Board Member of Whitman Walker Health, a DC-based federally-qualified health center focused on offering affirming community-based health and wellness services to all with a special expertise in LGBTQ and HIV care.

W. Gregory Feero, M.D., Ph.D., is a family medicine physician and human genetics specialist. Serving at Four Seasons Family Practice in Fairfield from 2001-06, Dr. Feero rejoined Maine General Medical Center's active staff at Four Seasons in July 2009 after working as chief of the Genomic Healthcare Branch of the National Human Genome Research Institute, National Institutes of Health in Bethesda, MD. Dr. Feero received a Doctorate in Human Genetics from the University of Pittsburgh Graduate School of Public Health and his medical degree from the University of Pittsburgh School of Medicine. He also serves as a faculty member in the Maine Dartmouth Family Medicine Residency program and is a Professor for the Department of Community and Family Medicine at the Geisel School of Medicine at Dartmouth in Hanover, NH. He is a co-chair for the Roundtable on Genomics and Precision Health of the National Academies of Sciences, Engineering and Medicine.

Chazeman S. Jackson, Ph.D., M.A., the Senior Director, Diversity, Equity & Inclusion of the American Society of Human Genetics, is an experienced health science researcher, public health administrator, and seasoned policy advisor. Most recently, Dr. Jackson served as a senior science policy analyst and the lead for the National Institutes of Health portfolio within the Office of the Assistant Secretary for Planning and Evaluation at the U.S. Department of Health and Human

Services. Dr. Jackson joined the department in 2010 as an Emerging Leader Fellow and a health science administrator at the National Institute on Minority Health and Health Disparities. From 2012 - 2016, she played an essential role, as health science advisor, developing and implementing the HHS Office of Minority Health's research and science policy agenda. Dr. Jackson earned a Bachelor of Arts degree in humanities with an emphasis in philosophy from Tougaloo College, a Master of Arts degree in biology from American University, and a Doctor of Philosophy in microbiology from Howard University. As a health advocate, Dr. Jackson commits her time and talents to a spectrum of public services that impact her community. She has received several honors and distinctions, including the American University Alumni Recognition Award and the United Negro College Fund's Outstanding Young Alumnus in 2004. She was an inaugural recipient of the Gates Millennium Scholarship and was a 2009 Christine Mirzayan Science and Technology Policy Fellow with the National Academies of Medicine's Roundtable on the Promotion of Health Equity and the Elimination of Health Disparities. Dr. Jackson has displayed commitment throughout her career to utilizing her scientific acumen and leadership skills to improve health and reduce the burden of disease, especially among vulnerable and marginalized groups.

Katherine Johansen Taber, Ph.D., is the Vice President of Clinical Product Research & Partnerships at Myriad Genetics. Her focus is on developing evidence and advancing initiatives to improve access to genetic testing in the women's health, oncology, and mental health areas. She leads a team conducting clinical and quantitative research, clinical data management, clinical trial operations, and publications. Most recently, she was Senior Director of Clinical Development in the Myriad Women's Health business unit. Before joining Myriad, she spent more than a decade at the American Medical Association, with a primary focus on educating providers about the clinical implementation of genomics and precision medicine, and on identifying and managing genomics and precision medicine policy issues affecting health care providers. She has held numerous positions on advisory committees and boards of organizations working to improve clinical adoption of genomic technology. Katie earned her Ph.D. in Molecular, Cell, and Developmental Biology at the University of California, Los Angeles, and conducted post-doctoral research at the USDA. She has held teaching appointments at UCLA, California State Polytechnic University, University of Idaho, and Columbia College Chicago.

Christa Lese Martin, Ph.D., FACMG, is the chief scientific officer at Geisinger. She's also a professor and the director of Geisinger's Autism & Developmental Medicine Institute. She previously held the position of associate chief scientific officer. Dr. Martin is a graduate of Penn State University and earned her doctorate in Human Genetics at the University of Pittsburgh. She's also board-certified by the American Board of Medical Genetics and Genomics in Clinical Cytogenetics. Her current research focuses on the identification and characterization of DNA changes in people with neurodevelopmental and neuropsychiatric disabilities, including autism. She is interested in determining the genetic cause for these disorders and correlating genotype with phenotype by genetic sub-type. She believes this "genotype-first" approach will lead to targeted treatments that can ultimately improve patient outcomes. Her research also focuses on evidence-based approaches to understanding genomic variation. Toward this goal, she's one of the principal investigators of the NIH-funded Clinical Genome Resource (ClinGen). Finally, Dr.

Martin is also part of the leadership team for the MyCode Community Health Initiative at Geisinger — a groundbreaking precision health initiative that's bringing genomic medicine into everyday healthcare.

Michelle Penny, Ph.D., is the Executive Vice President of Research & Development at Embark, Inc. Previously she was Vice President and Head of Genomics at Golfich Bio from January 2020 through February 2022. Prior to that, she was the Head of Translational Genome Sciences at Biogen. She received her Ph.D. in Genetics from the University of Birmingham, UK in 1993. After a postdoctoral fellowship in the Virology Division at the National Institute of Medical Research, Mill Hill, London, she joined Imperial College London, Department of Medical and Community Genetics where she was a postdoctoral research scientist until taking a lectureship in Human Molecular Genetics in 1998. Her academic research career focused on the study of complex polygenic diseases particularly autoimmune disease and susceptibility to infection. In 2002, Dr. Penny joined the Clinical Pharmacogenomics group at Pfizer in Sandwich, UK, and moved to New London, CT in 2006 to take on the role of Oncology Molecular Medicine Lead until 2009 when she moved to Indianapolis to lead the Pharmacogenomics work at Eli Lilly and Company.

Ryan Taft, Ph.D., is Director, Scientific Research at Illumina Inc. with a focus on the development and deployment of diagnostic whole genome sequencing worldwide, particularly for patients with rare and undiagnosed genetic disease. He obtained his Bachelor of Science in Biochemistry and Molecular Biology from the University of California, Davis on a Regent's Scholarship, and his Ph.D. in Genomics and Computational Biology from the University of Queensland on a U.S. National Science Foundation Research Fellowship. He was previously a Group Leader & Senior Research Fellow at the University of Queensland, where he still holds a minor appointment, and is Adjunct Associate Professor at the George Washington University School of Medicine and Health Sciences. He has published in a variety of well-regarded journals – including articles in *Nature Genetics*, *Nature Structural and Molecular Biology*, *the American Journal of Human Genetics*, and others. He is a founding member of the Global Leukodystrophy Initiative (GLIA), and is delighted to help drive solutions for patients with rare disease through Global Genes.

Catherine A. Wicklund, M.S., CGC, is the Senior Manager and Medical Science Liaison and Clinical Strategy Lead at Myriad Genetics. She is also an Adjunct Professor of Obstetrics and Gynecology (Clinical Genetics) at the Feinberg School of Medicine, Center for Genetic Medicine, Northwestern University. She has over 20 years of experience in clinical genetic counseling and has provided prenatal and pediatric genetic services. She served on the Board of Directors of the National Society of Genetic Counselors first as Region V Representative, then as Secretary and was President in 2008. Currently she is a member of the Illinois Department of Public Health's Genetic and Metabolic Diseases Advisory Committee, the Advisory Committee on Hereditable Disorders in Newborns and Children, the American Society of Human Genetics representative on the Scientific Program Committee of the 2016 International Congress of Human Genetics and the NSGC representative on the NASEM Roundtable on Genomics and Precision Health. Ms. Wicklund's research interests include issues regarding whole genome/exome sequencing and personalized medicine, psychosocial and counseling issues, and professional issues including workforce and access to and delivery of genetic services. She is a co-investigator on the

Electronic Medical Records and Genomics (eMERGE) Network, which aims to bring personalized medicine into broader clinical use. She received her Master of Science degree in Genetic Counseling from the University of Texas-Graduate School of Biomedical Sciences and is a diplomat of the American Board of Genetic Counseling.

Strategic Plan Reflection on the Roundtable's Work since 2020 and a Look Ahead

Roundtable on Genomics and Precision Health

November 15, 2023

SPEAKER GUIDANCE: CONTEXT AND QUESTIONS

Following the Genomics Roundtable's strategic plan development in 2020, the Shaping the Dialogue working group aims to accelerate the dissemination of actionable knowledge to shape practice and increase public awareness as well as to inform and influence how decisions are made. The goal of this session is to highlight the work of the Roundtable since the adoption of its strategic plan in 2020 and discuss what's next. Speakers should remind the audience that they are referring to past workshops and any views shared are their own perspectives from those workshops or related publications. Thank you for joining us for this session!

Questions to Frame Speakers' Talks:

1. Why did the Roundtable think that the event was important to hold? What were the main goals of the event?
2. What were the key takeaways that you heard from speakers during the event? What do you think could be done as a next step, either by the Roundtable or from others in the field?

Key Questions for Speakers to Start the Discussion:

1. What do you see as the impact of the workshop/webinar on the field of genomics and precision health? What groups were interested or engaged? What came of the event?
2. What area(s) do you think the Roundtable may focus on in the next year or so and why?

NATIONAL ACADEMIES Sciences Engineering Medicine

PREVENTING DISCRIMINATION, HARASSMENT, AND BULLYING:
POLICY FOR PARTICIPANTS IN NASEM ACTIVITIES

The National Academies of Sciences, Engineering, and Medicine (NASEM) are committed to the principles of diversity, inclusion, integrity, civility, and respect in all of our activities. We look to you to be a partner in this commitment by helping us to maintain a professional and cordial environment. **All forms of discrimination, harassment, and bullying are prohibited in any NASEM activity.** This policy applies to all participants in all settings and locations in which NASEM work and activities are conducted, including committee meetings, workshops, conferences, and other work and social functions where employees, volunteers, sponsors, vendors, or guests are present.

Discrimination is prejudicial treatment of individuals or groups of people based on their race, ethnicity, color, national origin, sex, sexual orientation, gender identity, age, religion, disability, veteran status, or any other characteristic protected by applicable laws.

Sexual harassment is unwelcome sexual advances, requests for sexual favors, and other verbal or physical conduct of a sexual nature that creates an intimidating, hostile, or offensive environment.

Other types of harassment include any verbal or physical conduct directed at individuals or groups of people because of their race, ethnicity, color, national origin, sex, sexual orientation, gender identity, age, religion, disability, veteran status, or any other characteristic protected by applicable laws, that creates an intimidating, hostile, or offensive environment.

Bullying is unwelcome, aggressive behavior involving the use of influence, threat, intimidation, or coercion to dominate others in the professional environment.

REPORTING AND RESOLUTION

Any violation of this policy should be reported. If you experience or witness discrimination, harassment, or bullying, you are encouraged to make your unease or disapproval known to the individual at the time the incident occurs, if you are comfortable doing so. You are also urged to report any incident by:

- Filing a complaint with the Office of Human Resources at 202-334-3400 or hrservicecenter@nas.edu, or
- Reporting the incident to an employee involved in the activity in which the member or volunteer is participating, who will then file a complaint with the Office of Human Resources.

Complaints should be filed as soon as possible after an incident. To ensure the prompt and thorough investigation of the complaint, the complainant should provide as much information as is possible, such as names, dates, locations, and steps taken. The Office of Human Resources will investigate the alleged violation in consultation with the Office of the General Counsel.

If an investigation results in a finding that an individual has committed a violation, NASEM will take the actions necessary to protect those involved in its activities from any future discrimination, harassment, or bullying, including in appropriate circumstances **the removal of an individual from current NASEM activities and a ban on participation in future activities**.

CONFIDENTIALITY

Information contained in a complaint is kept confidential, and information is revealed only on a need-to-know basis. NASEM will not retaliate or tolerate retaliation against anyone who makes a good faith report of discrimination, harassment, or bullying.

Updated December 2, 2021

BACKGROUND MATERIALS

Links to Additional Resources

Public Webcast - Strategic Plan Reflection on the Roundtable's Work since 2020:

- ASHG Podcast, *Genetically Speaking*, series on the Roundtable on Genomics and Precision Health https://learning.ashg.org/podcasts
- Improving Diversity of the Genomics Workforce (2021): Recordings and Proceedings in Brief https://www.nationalacademies.org/event/10-05-2021/improving-diversity-of-the-genomics-workforce-a-workshop
- Views and Voices: Reporting Genetics and Genomics (2022): Event information https://www.nationalacademies.org/event/06-22-2022/roundtable-on-genomics-and-precision-health-views-and-voices-reporting-genetics-and-genomics
- Realizing the Potential of Genomics across the Continuum of Precision Health Care (2022): Recordings and Proceedings https://www.nationalacademies.org/event/10-12-2022/realizing-the-potential-of-genomics-across-the-continuum-of-precision-health-care-a-workshop
- Next-Generation Screening – The Promise and Perils of DNA Sequencing of Newborns at Birth (2023): Recordings, Proceedings in Brief, and infographic https://www.nationalacademies.org/event/06-07-2023/next-generation-screening-the-promise-and-perils-of-dna-sequencing-of-newborns-at-birth-a-workshop