NATIONAL ACADEMIES *Sciences Engineering Medicine*

Board on Health Sciences Policy
Roundtable on Genomics and Precision Health

Sustaining Community Engagement in Genomics Research: A Workshop

July 17, 2024

In-Person Location
Keck Center
Room 100
500 Fifth Street NW
Washington D.C., 20001

Remote Log On Information
https://www.nationalacademies.org/event/42785_07-2024_sustaining-community-engagement-in-genomics-research-a-workshop

Roundtable on GENOMICS and PRECISION HEALTH

NATIONAL ACADEMIES Sciences Engineering Medicine

Board on Health Sciences Policy

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July 17, 2024

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AGENDA

Sustaining Community Engagement in Genomics Research: A Workshop

July 17, 2024

PURPOSE

A planning committee of the National Academies of Sciences, Engineering, and Medicine will organize and conduct a public workshop to examine how researchers could more meaningfully engage and sustain interactions with historically underrepresented communities in research to foster their participation in genomics and precision health studies. The overarching goal of the workshop is to help improve the quality of genomics research by understanding where obstacles to sustained community involvement remain.

The workshop may include invited presentations and discussions to:

- Understand limitations, both logistical (e.g., funding) and structural (e.g., past harms, lack of trustworthiness), to sustained community outreach and discuss possible solutions to those obstacles.
- Examine opportunities for researcher trainings related to sustained community outreach and engagement in genomics research.
- Discuss community engagement methods for genomics research with foundations, societies, patient groups, and other organizations about lessons learned from how they fund, engage, form, and measure success of partnerships with communities, other foundations/organizations, and researchers.
- Explore how community engagement methods for genomics research might differ when working with various underrepresented communities (e.g., LGBTQIA+, people with disabilities, racially minoritized groups, indigenous populations, women, geographically isolated groups).

The planning committee will organize the workshop, develop the agenda, select and invite speakers and discussants, and moderate or identify moderators for the discussions. Proceedings-in brief of the presentations and discussions at the workshop will be prepared by a designated rapporteur in accordance with institutional guidelines.

Please see the speakers' bios on page 22 of the briefing book to learn more about their expertise

Wednesday, July 17, 2023, 8:30 AM – 3:00 PM ET

Session I: Opening Remarks & Keynote

8:30–8:40 AM ET

Welcoming Remarks
Catherine (Cathy) Wicklund (she/her/hers), *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

8:40–8:50 AM

Introduction and Charge to the Workshop Speakers and Participants
Kellan Baker (he/him/his), *Workshop Planning Committee Co-Chair*
Executive Director
Whitman-Walker Institute

Sandra Soo-Jin Lee (she/her/hers), *Workshop Planning Committee Co-Chair*
Chief of the Division Ethics
Professor of Medical Humanities and Ethics
Columbia University

8:50–9:05 AM — **Keynote**

Joon-Ho Yu (he/him/his)
Adjunct Research Assistant Professor, Epidemiology
Research Assistant Professor, Pediatrics
University of Washington

9:05–9:30 AM — **Panel of Discussants from Populations**

Moderator: Vanessa Hiratsuka (she/her/hers), Southcentral Foundation

Andrea Schelhaas (she/her/hers)
Genetic Counselor
Nemours Children's Hospital

Julie Beans (she/her/hers)
Researcher
Southcentral Foundation

Cassandra Trimnell (she/her/hers)
Founder and Executive Director
Sickle Cell 101

Sarah Roth (she/they)
Genetic Counselor
Ph.D. Candidate
John Hopkins University

9:30–9:55 AM — **Panel Q&A**

Session II: Challenges and Opportunities for Sustaining Community Engagement and Partnerships in Genomics Research

Moderator: Amy Lemke (she/her/hers), University of Louisville, Norton Children's Research Institute

Objectives

- Explore the barriers (e.g., organizational, structural, project design) to sustaining community engagement in genomics research and their possible solutions.
- Examine how to engage communities in a way that promotes long-term relationships and builds trust.
- Discuss lessons learned in engaging communities in research projects. Touch on how engagement and partnership is or is not different for a genomics study.

9:55–10:10 AM

Krystal Tsosie (she/her/hers)
Assistant Professor
Arizona State University

10:10–10:25 AM

Lametra Scott (she/her/hers)
Founder and Executive Director
Breaking the SSickle Cell Cycle

10:25–10:40 AM

Kate Mittendorf (they/them/theirs)
Research Assistant Professor
Vanderbilt University Medical Center

10:40–11:10 AM **Panel Discussion**

11:10–11:25 AM **Break**

Session III: Methodologies to Sustaining Community Engagement and Partnerships in Genomics Research

Moderator: Sheri Schully (she/her/hers), NIH All of Us Research Program

Objectives

- Discuss different lengths of what sustaining means and includes (e.g., activities in project planning, recruitment/data collection/participant feedback at data collection, beyond the end of the project), funding sources, methodologies, and how to ensure what the community wants and needs are heard before starting a genomics study.
- Explore new approaches and resources to promote relationship building before specific research proposal submission, ensure relationships are built, and infrastructure is sustained after a project and/or funding ends.
- Discuss tools and training for conducting respectful community engagement in genomics research.

11:25–11:40 AM ET

Michele Gornick (she/her/hers)
Consultant
Health Data Matters
Adjunct Assistant Professor
Emory University

11:40–11:55 AM

Mitchell Lunn (he/him/his)
Associate Professor of Medicine (Nephrology)
Associate Professor of Epidemiology and Population Health, by courtesy
Co-Director, The PRIDE Study
Stanford University School of Medicine

11:55 AM–12:10 PM

Paulina Tindana
Senior Lecturer
University of Ghana School of Public Health

12:10–12:40 PM **Panel Discussion**

12:40–1:30 PM **Lunch Break**

Session IV: Measuring and Assessing Community Engagement and Partnerships in Genomics Research

Moderator: Natasha Bonhomme, Genetic Alliance, Expecting Health

Objectives

- Discuss how researchers can know if community engagement has been successful and examine how this aligns with the ways communities define success.
- Explore appropriate indicators and measures of community engagement and partnerships, specifically discussing tools for assessment.
- Discuss standardized metrics to assess the quality of the engagement process in genomics research to better guide future research or policy decisions.

1:30–1:45 PM ET

Ayodola Anise (she/her/hers)
Senior Director
Milken Institute

1:45–2:00 PM

Tabia Henry Akintobi (she/her/hers)
Professor and Chair Community Health and Preventive Medicine
Morehouse School of Medicine

2:00–2:15 PM

Karriem Watson (he/him/his)
Chief Engagement Officer
NIH All of Us Research Program

2:15 –2:45 PM

Panel Discussion

Session V: Final Reflections

2:45–3:00 PM

Wrap Up
Kellan Baker (he/him/his), *Workshop Planning Committee Co-Chair*
Executive Director
Whitman-Walker Institute

Sandra Soo-Jin Lee (she/her/hers), *Workshop Planning Committee Co-Chair*
Chief of the Division Ethics
Professor of Medical Humanities and Ethics
Columbia University

ANNOUNCEMENTS

NATIONAL ACADEMIES *Sciences Engineering Medicine*

Roundtable on Genomics and Precision Health

National Cancer Policy Forum

Upcoming Workshop!

Examining Clinical Guidelines for the Adoption of Genomic Testing: A Workshop

October 29, 2024

Washington D.C.

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 clinical practice guidelines can impact adoption of genomics into routine medical care. The workshop will examine how guidelines for genomic testing are developed by various organizations and implemented within clinical practice, with a focus on exploring inconsistencies across guidelines.

The workshop's presentations and discussions may focus on:

- Exploring the processes and methodologies used by different professional societies, organizations, and collaborations to gather evidence and develop clinical guidelines for appropriate genomic testing.
- Understanding how clinicians, payers, test developers, laboratory partners, and others decide which guideline(s) to follow and how they use these guidelines in practice.
- Examining elements that are consistent and those that differ across clinical guidelines for genomics and how these areas impact access, coverage, and equity in care for patients and how they affect clinicians, payers, test developers, laboratories, and others.
- Discussing opportunities for a possible path forward for more compatible clinical guidelines for genomics to improve patient 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 proceedings-in brief of the presentations and discussions at the workshop will be prepared by a designated rapporteur in accordance with institutional guidelines.

NATIONAL ACADEMIES *Sciences Engineering Medicine*

October 2024: Upcoming Consensus Study Report Release!

The Use of Race & Ethnicity in Biomedical Research

Statement of Task

An ad hoc committee of the National Academies of Sciences, Engineering, and Medicine will assess the current use of the social constructs of race and ethnicity in biomedical research and provide recommendations to guide the scientific community in the future use of race and ethnicity in biomedical research.

More specifically, the committee will:

- Document and evaluate how racialized group and ethnic categories are currently being used in biomedical research (e.g., as a descriptor, to stratify data, to apply race norming, to infer differences between groups due to environmental and social impacts), including describing consequences and contributions to health inequities in current clinical practices;
- Identify the circumstances in which it is appropriate to use the social constructs of race and ethnicity in biomedical research, for example in studying the health effects of racism, and the circumstances in which race and ethnicity should not be used to inform inferences;
- Review existing guidance for researchers on the use of race as a variable in biomedical research.

Based on its review of the literature and other expert input, the committee will develop a report with its findings, conclusions, and recommendations for entities such as researchers, funders, publishers, scientific and medical societies, health systems, and industry regarding:

- The use of race and ethnicity in biomedical research, including identifying current practices that should be continued, stopped, or modified.
- Policy changes to reform the use of race and ethnicity in biomedical research, with specific attention to the practice of race norming or race correction.
- Implementation strategies to help enhance the adoption of best practices across the biomedical research community.

The committee's work will focus on the use of racialized group and ethnic categories across the spectrum of biomedical research, including the development of clinical prediction models and other clinical decision tools. Related topics in the provision of clinical care, such as inequitable access to health care and racism in care delivery, are beyond the scope of this study.

NATIONAL ACADEMIES *Sciences Engineering Medicine*

Committee Members

Chair

M Roy Wilson, M.D., M.S.
Wayne State University

Members

Alisson E. Aiello, Ph.D.
Columbia University

Efrén J. Flores, M.D.
Massachusetts General Hospital

Carmene Guerra, M.D., M.S.C.E.
University of Pennsylvania

Elizabeth Heitman, Ph.D.
University of Texas Southern Medical Center

Matthew F. Hudson, Ph.D., M.P.H.
Prisma Health

Husseini K. Manji, M.D.
Oxford University

Amy Moran-Thomas, Ph.D.
Massachusetts Institute of Technology

Margaret Moss, Ph.D., J.D., RN
University of Minnesota School of Nursing

Elizabeth O. Ofili, MD., M.P.H.
Morehouse School of Medicine

Neil R. Powe, M.D., M.P.H., M.B.A.
University of California, San Francisco

Aliya Saperstein, Ph.D.
Stanford University

Roland Thorpe, Jr., Ph.D.
Johns Hopkins Bloomberg School of Public Health

Shyam Visweswaran, M.D., Ph.D.
University of Pittsburgh

Genevieve L. Wojcik, Ph.D.
John Hopkins Bloomberg School of Public Health

Ruqaiijah Yearby, J.D., M.P.H
The Ohio State University

Funded by the Doris Duke Foundation and the Burroughs Welcome Fund

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.

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

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

Geoff Hollett, Ph.D.
American Medical Association

Adriana Huertas-Vazquez, Ph.D.
Illumina. Inc.

Praduman Jain, M.S.
Vibrent Health

Katherine Johansen Taber, Ph.D.
Myriad Genetics

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, M.D., Ph.D.
Global Genomic Medicine Collaborative (G2MC)

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

Debra Leonard, M.D., Ph.D.
University of Vermont Health Network

Christa Lese Martin, Ph.D., FACMG
Geisinger

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

Adele Mitchell, Ph.D.
Biogen

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

Judy Mouchawar, M.D., M.S.P.H.
Blue Cross Blue Shield Association

David Nelson, Ph.D.
American Society for Human Genetics

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

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

Jacquelyn Taylor, Ph.D., PNP-BC, RN, FAHA, FAAN
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

Karen Weck, M.D.
College of American Pathologists

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., PMP, *Roundtable Director*
Kathryn Asalone Shively, Ph.D., *Associate Program Officer*
Michelle Drewry, Ph.D., *Associate Program Officer*
Ashley Pitt, *Senior Program Assistant*
Kingsly Mante Angua, *Summer Intern*

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.

WORKSHOP INFORMATION

NATIONAL ACADEMIES *Sciences Engineering Medicine*

Board on Health Sciences Policy

Roundtable on Genomics and Precision Health

Sustaining Community Engagement in Genomics Research: A Workshop

July 17, 2024

Planning Committee Member Roster

Co-Chairs

Kellan Baker, Ph.D., M.P.H., M.A.
(he/him/his)
Executive Director
Whitman-Walker Institute

Members

Natasha Bonhomme
Chief Strategy Officer
Genetic Alliance
Founder
Expecting Health

Yue Guan, Ph.D., M.S. (she/her/hers)
Associate Professor
Certified Genetic Counselor
Co-Director of Emory Precision Public Health Research Program
Behavioral, Social, & Health Education Sciences
Rollins School of Public Health, Emory University

Vanessa Hiratsuka, Ph.D., M.P.H. (she/her/hers)
Senior Researcher, Research Department
Southcentral Foundation Co-Director
National Resource Center for Alaska Native Elders (NRC-ANE)

Sandra Soo-Jin Lee, Ph.D.
(she/her/hers)
Chief of the Division Ethics
Professor of Medical Humanities and Ethics
Columbia University

Amy Lemke, Ph.D., M.S (she/her/hers)
Professor of Pediatrics
University of Louisville
Director of Community Engaged Research
Norton Children's Research Institute

Sheri Schully, Ph.D. (she/her/hers) Deputy Chief Medical & Scientific Officer All of Us Research Program, NIH

Joyce Tung, Ph.D. (she/her/hers)
Vice President of Research
23andMe

Joseph Yracheta, M.S.
Executive Director
Native BioData Consortium

NATIONAL ACADEMIES Sciences Engineering Medicine

Board on Health Sciences Policy

Planning Committee Member Biographies

Kellan E. Baker, Ph.D., M.P.H., M.A. (he/him/his), is the Executive Director of Whitman-Walker Institute, which leverages cutting-edge research, policy, and education to advance health equity nationwide, particularly for LGBTQI+ people and people living with HIV. The Institute is affiliated with Whitman-Walker Health, a Federally Qualified Health Center with more than 50 years of service to diverse communities in Washington, D.C. and beyond. Kellan is a nationally-known health services researcher, educator, and health policy professional with specific expertise in areas such as health equity, LGBTQI+ health, community engagement in research, and sexual orientation and gender identity (SOGI) data collection. Kellan has worked with the National Academies of Sciences, Engineering, and Medicine on multiple studies related to LGBTQI+ health and is a Principle Investigator on a major award from the National Human Genome Research Institute to develop community-driven guidelines for genomics research with transgender populations. He holds appointments as associate faculty in the Departments of Health Policy and Management at the George Washington University and the Johns Hopkins School of Public Health and received his Ph.D. from Johns Hopkins, an M.P.H. and M.A. from the George Washington University, and a B.A. with high honors from Swarthmore College.

Sandra Soo-Jin Lee, Ph.D. (she/her/hers), is Chief of the Division of Ethics and Professor of Medical Humanities & Ethics at Columbia University. Trained as a medical anthropologist, Dr. Lee's research focuses on ethics, equity and justice in the development and application of emerging biotechnologies. She has extensive experience leading multi-disciplinary research funded by the National Institutes of Health (NIH) including the JUSTICE Study: Just Inclusion and Equity: Negotiating Community-Research Partnerships in Genomics Research. She publishes broadly in the science, medical, bioethics, and social science literatures, and co-edited Revisiting Race in a Genomic Age (2008). Dr. Lee serves as President of the Association of Bioethics Program Directors and Co-Director of the NIH funded Center for ELSI Resources and Analysis and the ELSI Congress. She is a Hastings Center Fellow and was a Rockefeller Foundation Fellow in the Humanities, a Wenner-Gren Foundation Fellow, a University of Edinburgh Bright Ideas Fellow, and a Fellow at the School for Advanced Research. Dr. Lee serves on the editorial boards of the American Journal of Bioethics and Narrative Inquiry in Bioethics, and on the US Health and Human Services Secretary's Advisory Committee on Human Research Protections. Dr. Lee received her doctorate in Medical Anthropology from the University of California, Berkeley and San Francisco program and her undergraduate degree in Human Biology and postdoctoral training from Stanford University.

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.

Yue Guan, Ph.D., M.S. (she/her/hers), is a board-certified genetic counselor and social behavioral scientist. She holds a Masters of Science in Genetic Counseling and a Ph.D. in Public Health from Johns Hopkins University. Dr. Guan's research work has focused on promoting population health and eliminating health inequities through effective translation of evidence-based genomic-informed programs and policies. She has led or served as a co-investigator on projects related to: effective communication of genetic risk, implementation and dissemination of evidence-based genomic applications, and community engagement to expand the reach of genomic services to racial/ethnic minorities and rural communities. Dr. Guan is the Co-director of the Emory Precision Public Health Research Program. She currently holds leadership positions on the American Public Health Association (APHA) Genomic Forum Leadership Team, the Board of Directors for the National Society of Genetic Counselors (NSGC), and the Chair of Equity Action Group of NCI Consortium for Cancer Implementation Science (CCIS).

Vanessa Hiratsuka, Ph.D., M.P.H. (Diné/Winnemem Wintu; enrolled member of the Navajo Nation, she/her/hers), is a Senior Researcher at Southcentral Foundation, a tribal health organization in Anchorage, Alaska. She received a bachelor's degree in human biology from Stanford University, a master's degree in public health practice from the University of Alaska Anchorage, and a doctoral degree in public health from Walden University. She uses Indigenous Research Methods and her community-engaged research work has spanned regional, national, and international efforts. Her research interests include ethical, social, and legal implications of genomic research and precision medicine among Indigenous populations; evaluation of health interventions in public schools; and evaluation of health and training programs serving individuals experiencing intellectual and developmental disabilities.

Amy A. Lemke, Ph.D., M.S. (she/her/hers), is a Professor of Pediatrics in the Division of Clinical and Translational Research at the University of Louisville. She is also Director of Community Engaged Research at Norton Children's Research Institute, affiliated with the University of Louisville. As Director, she leads a Research Core to support investigators in the use of qualitative approaches, survey design, and mixed methods in their research programs. Dr. Lemke is experienced in conducting multi-site studies aimed at assessing genomic research and clinical innovations and the impact on individuals, providers, and healthcare organizations. Her expertise includes the use of community engaged research strategies, such as community-based

participatory research and deliberative engagement, to collaborate with underrepresented and minoritized populations in genomic testing research. Dr. Lemke's current research focuses on: outcomes of genomic screening in a variety of settings; the utility of genomic testing for individuals, caretakers and providers; and factors that influence genomic test access and results utilization in varied populations. Additionally, she leads practice guidance and policy efforts in addressing underrepresentation in genomics research and genomics-enabled healthcare.

Sheri Schully, Ph.D. (she/her/hers), is the deputy chief medical and scientific officer and the lead for ancillary studies in the All of Us Research Program at the National Institutes of Health. Through her leadership, she is establishing ancillary studies as a core and scalable capability of the program that will expand the cohort and deliver new phenotypic, lifestyle, environmental, and biological data to the All of Us Researcher Workbench. Dr. Schully has been involved with shaping the program and setting the scientific vision and strategy since its inception. Prior to this role, she was a team lead and senior advisor for disease prevention in the Office of Disease Prevention (ODP). There, she led the effort to systematically monitor NIH investments in prevention research and assess the progress of that research. She also served as the team lead for the Knowledge Integration Team as well as a program officer in the Epidemiology and Genomics Research Program at the National Cancer Institute (NCI). She came to the NIH as an NCI-designated Presidential Management Fellow in 2005. Dr. Schully's research interests include genomics, personalized medicine, and the integration of genetic and genomic information into clinical and public health practices. Her work has been published in numerous high-impact scientific journals.

Joyce Tung, Ph.D. (she/her/hers), is Vice President of Research at 23andMe and is responsible for 23andMe's human genetics research program of over ten million consented participants, including recruitment and data collection, new methods and tools development, genetic discovery for therapeutic target identification and validation, and academic and industry research collaborations. Since joining 23andMe in 2007, Joyce has been part of many of the company's key milestones - the launch of the consumer product, the first scientific publications and collaborations, the FDA authorization of genetic reports, and the launch of the therapeutics division. Before 23andMe, Joyce earned her Ph.D. in Genetics from the University of California, San Francisco where she was a National Science Foundation graduate research fellow and was a postdoctoral fellow at Stanford University.

Joseph Yracheta, M.S. (Pūrepecha – Mexican Indigenous), is the Executive Director and Board Vice President of Native BioData Consortium. He is building a career in Pharmacogenomics and Environmental Forensics using the cutting edge tools of Omics. Yracheta places an emphasis on American Indian and Latin Indigenous Public Health and Bioethics of research in Indigenous communities to highlight and transform the socio-economic injustice and health disparity in the Amerindigenous of the Western Hemisphere and Polynesia. He has taught STEM courses at various reservation high schools in South Dakota. Yracheta graduated from Loyola University-Chicago in 1993 with a B.S. in Psychology, but also had over 28 credit hours in Biology. Joseph has a Masters in Pharmacogenomics from University of Washington and is currently a DrPH candidate in Epidemiology at Johns Hopkins University.

NATIONAL ACADEMIES Sciences Engineering Medicine

Board on Health Sciences Policy

Roundtable on Genomics and Precision Health

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July 17, 2024

Speaker Biographies

Tabia Henry Akintobi, Ph.D., M.P.H. (she/her/hers), is Professor and Chair of the Department of Community Health and Preventive Medicine at Morehouse School of Medicine. She is a globally sought social behavioral scientist and public health practitioner leading or collaborating in community-driven translational research and programs contributing to the eradication of health disparities thereby advancing community and population health transformation. She is Principal Investigator of a Prevention Research Center funded by the Centers for Disease Control and Prevention designed to advance the art and implementation science of community-based participatory research grounded in community governance. She is also principal investigator, lead or advisor for other local and national centers, institutes and networks funded by the National Institute of Diabetes and Digestive and Kidney Diseases, the National Institute on Minority Health and Health Disparities, the National Center for Advancing Translational Sciences and the Department of Health and Human Services, among many others. She is an extensively published contributor to the peer reviewed literature and co-author of texts including *The Morehouse Model: How School of Medicine, Revolutionized Community Engagement and Health Equity* and the 2nd and 3rd editions of the globally recognized *Principles of Community Engagement Primer*. As Associate Dean for Community Engagement, she facilitates or amplifies community-centered, equity-driven, evidence-based multisectoral partnerships that advance health equity and justice. Her work is guided by graduate training in public health, with specializations in social marketing, community-based participatory research, and evaluation.

Ayodola Anise, M.H.S. (she/her/hers), is the senior director of operations working across FasterCures, Public Health, Future of Aging, and Feeding Change where she advances organizational strategy, effectiveness, efficiency, and equity. Anise brings programmatic expertise on community engagement, health and health care quality and equity, and patient-centered comparative effectiveness research (CER). Most recently, Anise served as the deputy director for the National Academy of Medicine Leadership Consortium for a Learning Health System, translating the mission and vision into strategic approaches across the areas health equity; evidence generation; digital health; and value incentives and systems. Previously, Anise worked as a senior program officer for the Patient-Centered Outcomes Research Institute (PCORI) where she managed a $78 million patient-centered CER portfolio to improve health care systems and health care equity and led initiatives to foster collaboration among researchers and

partners. Before joining PCORI, Anise worked at the Engelberg Center for Health Care Reform at the Brookings Institution, as a senior associate for the Lewin Group, a health care research and consulting firm, and as a project coordinator for a study on women's health at Georgetown University. Anise earned a bachelor's in English writing with minors in chemistry and biology from the University of Pittsburgh and a Master of Health Science from the Johns Hopkins Bloomberg School of Public Health.

Julie Beans, M.P.H. (she/her/hers) (Yup'ik and Oneida), is a public health researcher who has worked with Southcentral Foundation Research since 2014. Ms. Beans has led several community-based research projects that aim to improve health outcomes for the Alaska Native and American Indian community in Alaska through research, while maintaining community protections. Ms. Beans works to bring the voice of community members to the forefront of health research, including genomic research, to ensure research directly benefits the community.

Michelle Gornick, Ph.D., M.A. (she/her/hers), is an independent consultant and Adjunct Assistant Professor in the Department of Behavioral/Social/Health Education at Emory University, School of Public Health. She is a cross-disciplinary scientist with expertise in the areas of genetics, statistics, social/behavioral sciences, and bioethics. She is trained in both quantitative and qualitative methods and has experience in survey development, user-centered design, as well as principles of democratic deliberation. She has experience in using these methods to solicit informed preferences of underrepresented voices in the return of genomic test results, newborn screening, and cancer screening. She has led several projects in collaboration with the Department of Veteran Affairs National Center for Ethics in Health Care, the Iowa Department of Public Health, women of African Ancestry, and Hispanic/Latino community members in southeast Georgia. She is particularly excited about the opportunity to extend this work to improving healthcare engagement

Mitchell (Mitch) R. Lunn, M.D., MAS, FACP, FASN (he/him/his), is an Associate Professor of Medicine (Nephrology) and of Epidemiology and Population Health at Stanford University School of Medicine. Dr. Lunn is a physician-scientist investigating sexual and gender minority (SGM) health using existing and emerging technologies to better characterize the health and well-being of these communities that are underrepresented in biomedical research. He is the co-director of The PRIDE Study (pridestudy.org), a national, online, prospective, longitudinal general health cohort study of over 30,000 SGM adults. Dr. Lunn is also the co-director of PRIDEnet, a national community engagement network that aims to involve SGM communities in all stages of the biomedical research process. Dr. Lunn earned a Bachelor of Science degree in biology and French with highest thesis honors from Tufts University in 2004, a Doctor of Medicine degree from Stanford University School of Medicine in 2010, and a Master's in Advanced Studies degree in Clinical Research from the University of California, San Francisco (UCSF) in 2017. He completed internal medicine internship and residency training at Brigham and Women's Hospital in 2013 and nephrology fellowship at UCSF in 2016. Dr. Lunn maintains board certification in internal medicine, nephrology, and clinical informatics.

Kathleen ("Kate") F. Mittendorf, Ph.D. (they/them/theirs), is a Research Assistant Professor of Medicine in the Division of Hematology and Oncology, Department of Medicine, Vanderbilt University Medical Center (VUMC). Their career mission is to improve the health equity of cancer and genomic medicine services delivery, using their skills and expertise across research, informatics, genomics, electronic application development, clinical operations, community engagement, and care delivery. In their current role, Dr. Mittendorf leads several aspects of operations, development, and implementation of precision medicine care delivery research. They currently lead two sexual and gender minority supplements to large clinical trials (3U01HG1118-04S1 and 3U01CA232829-01A1S1) to improve genomic health equity in transgender, gender-diverse and sex-diverse individuals. They are co-Investigator on work related to community-engaged, equitable implementation of the PREMM5 and PREMMplus hereditary cancer risk assessment applications, in collaboration with Dr. Sapna Syngal of Dana-Farber Cancer Institute. They also act as the electronic health records integration site lead for the VUMC site of the eMERGE Network and are a scientific contributor to the FOREST clinical trial, the GE Healthcare-VUMC digital precision oncology partnership, the Oncology Knowledge Rapid Alerts clinical decision support project, and other precision medicine care delivery research efforts. Further, they are the Research II Course Co-Director in the Vanderbilt University Master of Genetic Counseling Program. Prior to their current role at VUMC, they worked at Kaiser Permanente Northwest Center for Health Research, where they led large aspects of a large health equity-focused genomics services delivery clinical trial, including the community-engaged literacy adaptation of provider-facing risk assessment web applications for use as patient-facing tools in marginalized populations. There, they also received a NIH Research Supplement to Promote Diversity in Health-Related Research at the investigator level, during which they solidified their expertise in scientific project leadership and evaluation of electronic health applications in medically marginalized populations. Dr. Mittendorf completed their Ph.D. in biochemistry at Vanderbilt University, with the support of a National Science Foundation Graduate Research Fellowship.

Sarah Roth, M.F.A. (she/they), is a genetic counselor and Ph.D. candidate in Anthropology at Johns Hopkins University. A BRCA1 carrier, Sarah's research focuses on the experiences of patients, communities, and providers in cancer care and genomic medicine. Sarah is a founding editor of *Tendon* at JHU's Center for Medical Humanities & Social Medicine, a contributing writer at *Synapsis: A Health Humanities Journal*, and a recent predoctoral fellow in Bioethics at the National Institutes of Health.

Andrea Schelhaas, CGC (she/her/hers), is a genetic counselor on the multidisciplinary skeletal dysplasia and OI teams at Nemours Children's Hospital in Wilmington, DE. She has served in her current role since 2019. In addition to seeing patients clinically, she has a special interest in caring for patients and families in the prenatal and intensive care setting who have received a lethal or likely-lethal diagnosis in the perinatal period. She is also a member of the Nemours' Ethics and Patients' Rights Committee and a member of the American College of Medical Genetics (ACMG) Diversity Equity and Inclusion committee. As a genetic counselor with achondroplasia, Andrea finds it important to address factors that may influence a disabled individual's experiences in society and within the medical system and increase the representation

of disabled individuals in the healthcare setting. Prior to her work as a genetic counselor, Andrea was a special education teacher.

Dr. Lamerta Scott, Pharm.D., CCHP (she/her/hers), is a distinguished figure in the healthcare sector, holding the roles of Founder and CEO of Breaking The Sickle Cell Cycle Foundation, Inc., and Director of Pharmacy for the Tennessee Department of Correction. With over two decades of experience in pharmacy, she has become a trusted pharmacy consultant, specializing in managed care pharmacy and the development of cost-effective strategies to enhance pharmaceutical care and patient health outcomes. Beyond her professional endeavors, Dr. Scott is a devoted mother, intimately acquainted with the challenges that come with caring for a child with sickle cell disease. In 2015, driven by her experiences in managed care and community pharmacy, she founded Breaking The SSickle Cell Cycle Foundation, Inc. a non-profit dedicated to sickle cell disease. This organization serves as a beacon for community awareness, education, and prevention initiatives. Dr. Scott's impact extends beyond the pharmacy realm; she has taken a lead in educating communities and healthcare professionals about sickle cell disease. Her efforts have garnered recognition, including an accolade from former Nashville Mayor John Cooper for her outstanding contributions to sickle cell disease education and awareness. Her story has been featured in prestigious publications like the New York Times and the CDC's website, earning her the Power Moves Award for extraordinary community service. Notably, Dr. Scott has received the Presidential Certificate of Appreciation from the Clarksville Branch of the NAACP and the Music City USA Gold Record award for her advocacy work in Nashville. Her dedication to academic development is evident through her contributions to student pharmacist education and her didactic presentations on sickle cell disease to various healthcare groups. Dr. Scott is a well-educated professional, holding a Doctorate of Pharmacy degree from the University of Tennessee College of Pharmacy and a Bachelor of Science degree in Biology from the University of Memphis. Her contributions to sickle cell research, published in the Journal of Health Care for the Poor and Underserved, underscore her commitment to advancing knowledge in the field. With a firm belief in patient engagement and inclusion, Dr. Scott remains at the forefront of developing best practices for serving the sickle cell community. Her multifaceted contributions and unwavering advocacy efforts continue to make a lasting impact on healthcare, education, and community well-being.

Paulina Tindana, D.Phil., is an Associate Professor and Bioethicist at the Department of Health Policy, Planning and Management, University of Ghana School of Public Health. Her teaching and research interests lie in the ethical, socio-cultural and policy implications of biomedical research and public health systems, including genetics and genomics research. She is the Principal Investigator of the Genomics Epidemiology for Malaria Elimination Policy Engagement Project, under the Pathogen Diversity Network, Africa (PDNA) with funding from the Gates Foundation. She is also an MPI for H3Africa Community Engagement in Genomics and Biobanking (CEBioGen) project, which is supported by the NHGRI/NIH.

Cassandra Trimnell (she/her/hers), is a prominent advocate for individuals living with sickle cell disease, having founded and currently serving as the executive director of Sickle Cell 101 (SC101), a non-profit organization that aims to educate, empower, and connect the global sickle

cell community through targeted digital engagement and data-driven initiatives. Trimnell herself was the first child diagnosed with sickle cell disease through the Iowa Newborn Screening Program in 1987, which has motivated her work to address knowledge gaps, priorities, and needs of the global sickle cell community, general public, and healthcare professionals. Under her leadership, SC101 has grown significantly and currently hosts the largest and most comprehensive digital platforms for real-time generated community insights and patient experience data. SC101's social media platforms has over 50,000 followers based in over 115 countries and is a leading and reliable source of information and support for people affected by sickle cell disease, reaching millions annually. Trimnell received her Bachelor of Arts degree in Global Studies - Social, Political, and Economic Development from Sonoma State University and later completed the Sickle Cell Educator certification issued by the California Department of Public Health and Hemoglobinopathy Counseling Training through Cincinnati Children's Hospital. Her expertise has been recognized by numerous organizations and institutions, including being awarded the "Community Champion" award from the Sickle Cell Disease Association of America in 2020. In addition to her work with SC101, Trimnell is a sought-after speaker and consultant on sickle cell disease, serving as a patient advocate on various boards and committees, including the NIH-NHLBI's Sickle Cell Disease Advisory Committee and the American Society of Hematology's Sickle Cell Disease Coalition. She has also worked on several significant projects, including the New England Journal of Medicine's "Sickle Cell and Gene Therapy Patient and Physician Perspectives" video series, NHLBI's Cure Sickle Cell Initiative, SWAY and SHAPE global survey studies, and featured on the BET show "The Rundown with Robin Thede: Pain and Prejudice" episode. Trimnell's tireless efforts and unwavering dedication to the sickle cell community have made her a respected leader and advocate for all stakeholders impacted by sickle cell disease. Her expertise and achievements have encouraged and progressed innovation within education, research, and awareness, improving the lives of countless individuals and families affected by sickle cell disease.

Krystal Tsosie, Ph.D., M.P.H, M.A. (she/her/hers), is an Assistant Professor in the School of Life Sciences at Arizona State University. She is also Associate Director of the Biodiversity Knowledge Integration Center at ASU. She also co-founded the Native BioData Consortium, the first Indigenous-led biological and data repository operating within the jurisdictional bounds of a US Tribal Nation. Her genomics research interests are specific to Indigenous communities and people in health, biomedicine, conservation biology, and paleogenomics. She is also an expert in bioethics, data policy and governance, and developing digital data tools rooted in machine learning approaches to advance the sharing and informed consent of genomic data. Her research and Indigenous community advocacy are challenging ethical norms of research and policy across scientific disciplines. Her work is internationally covered in the media, and she is on ethical advisory boards for many national and international government and science policy organizations, including work with the National Academies of Sciences, Engineering, and Medicine; the World Health Organization; the American Society of Human Genetics; and others. She is a National Academies Kavli Fellow and an ENRICH Global Scholar for Indigenous data technologies.

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Board on Health Sciences Policy

Karriem S. Watson, DHSc, MS, MPH (he/him/his), is the Chief Engagement Officer for the National Institutes of Health's All of Us Research Program. He leads the All of Us Research Programs efforts to foster relationships with participants, communities, researchers and providers across the United States and territories through equitable engagement to help build one of the largest and most diverse health datasets of its kind to advance precision medicine research. Prior to joining the NIH, Dr. Watson spent over 15 years conducting cancer disparities research. He completed his post-doctoral training in cancer center leadership under Dr. Robert A. Winn at the University of Illinois at Chicago Cancer Center and went on to become an independent funded researcher with funding from the NCI, NIMHD and NHLBI. Dr. Watson's work spans across community engaged research, CBPR, and implementation and dissemination science including engaging community members as Citizen Scientists to improve diversity, equity, and inclusion in clinical trials. In addition to his research, Dr. Watson also served as a health care administrator overseeing community-based research and serving as the Associate Executive Director for a network of Federally Qualified Health Centers (FQHCs). Dr. Watson has been recognized by many organizations for his commitment to training and education including being awarded an Innovator in STEM award by the Chicago Urban League.

Joon-Ho Yu, Ph.D., M.P.H. (he/him/his), is a Research Assistant Professor of Pediatrics at the University of Washington School of Medicine (UWSOM); Associate Director of the Institute for Public Health Genetics at the UW School of Public Health (UWSPH); and a member of the Treuman Katz Center for Pediatric Bioethics and Palliative Care at Seattle Children's Research Institute (SCRI). Joon also holds adjunct appointments in the UWSOM Department of Bioethics and Humanities and UWSPH Department of Epidemiology. Joon is a graduate of Carleton College and received his M.P.H. and Ph.D. in Public Health Genetics from the University of Washington. Joon also serves as Deputy Director and Director of Data, Assessment, Research and Evaluation at the Korean Community Service Center of Seattle, a community-based organization that serves Korean Americans throughout Western Washington. At the intersection of these varied roles, Joon conducts and studies community-centered research on topics such as genome sequencing, big health data, parenting/caregiving and early childhood development, community-based behavioral health, and community safety.

Sustaining Community Engagement in Genomics Research: A Workshop
Roundtable on Genomics and Precision Health

July 17, 2024

Keck 100
500 5th Street NW
Washington, D.C. 20001

SPEAKER GUIDANCE: CONTEXT AND QUESTIONS

Following the Genomics Roundtable's strategic plan development in 2020, the Equity working group seeks to foster action related to underrepresentation and inequities in genomic research, the workforce, and access to genomic services by people who need them. The goals of this workshop are to examine how researchers could more meaningfully engage and sustain interactions with historically underrepresented communities in research to foster their participation in genomics and precision health studies and to help improve the quality of genomics research by understanding where obstacles to sustained community involvement remain. Thank you for joining us for this session!

SESSION I: Keynote & Community Panel

Questions to frame the keynote talk [Note: to the extent that you can, please share concrete examples and case studies when responding to these questions]:

1. What is community engagement? Community-engaged research? What is not community engagement?
2. What are the goals of community engagement? What is community engagement for?
3. What are the historical examples and context-specific considerations researchers need to consider when conducting and sustaining community partnerships that support research in human genomics?
4. What does a commitment to sustained community engagement require of researchers, communities, and institutions?

Key questions for panelists:

5. What does successful engagement look like?
6. Describe a successful engagement experience with a genomics research project. What worked well? What could the researchers have done differently?
7. What does meaningful, productive, and high quality community engagement look like in your community? Who decides what meaningful, productive, and high quality is? How does it look different from what it might look like in another community?
8. How is community engagement and partnership different in genomics research projects versus other areas of research?

SESSION II: Challenges & Opportunities for Sustaining Community Engagement and Partnerships in Genomics Research

Questions to frame the keynote talk [Note: to the extent that you can, please share concrete examples and case studies when responding to these questions]:

1. What are the organizational, structural, and project design barriers to sustaining community engagement in genomics research? What are some possible solutions?
2. How can researchers and their institutions become more trustworthy within communities? What are some lessons learned from engaging communities within a genomics research project?
3. How is community engagement and partnership different in genomics research versus other areas of research?

Key questions for speakers:

4. What does successful engagement look like?
5. How has the progression of genomics research (e.g., Large international consortia) and the integration of increasing array of individual and population-based data created new challenges and opportunities for integrating the role and interests of communities?
6. How can or is sustained community engagement before and beyond the traditional genomics project supported?
7. What is the role of community engagement in addressing controversies around accessing genomic information from non-consented sources?

SESSION III: Methodologies to Sustaining Community Engagement and Partnerships in Genomics Research

Questions to frame the keynote talk [Note: to the extent that you can, please share concrete examples and case studies when responding to these questions]:

1. How are communities involved in genomics research projects throughout the project lifecycle and beyond? With whom is this relationship being sustained both formally and informally (e.g., research team, institution)?
2. How might community engagement look differently when the engagement is sustained by the research team versus the institution?
3. How does researchers' commitment to sustaining community engagement and partnerships impact whether communities chose to participate in research or not?
4. How can sustained community engagement before and beyond the traditional genomics project be supported (e.g., funding, methodology, training)?

Key questions for speakers:

5. What does successful engagement look like?
6. What are some resources or approaches researchers can use to promote relationship building with communities before a project proposal is submitted?
7. What are some tools and trainings that researchers could leverage to conduct respectful community engagement in genomics research?

SESSION IV: Measuring and Assessing Community Engagement and Partnerships in Genomics Research

Questions to frame the keynote talk [Note: to the extent that you can, please share concrete examples and case studies when responding to these questions]:

1. What are appropriate indicators or measures of community engagement and partnership? Are there specific measures used in genomics research? Discuss specific examples and lessons learned.
2. What frameworks and tools are used or needed in order to measure and assess community engagement in genomics research? Discuss the necessary rigor of these tools to have impact. What does the implementation of these tools look like?

Key questions for speakers:

3. What does successful engagement look like?
4. How do the measures and assessments researchers use to analyze community engagement compare to those that the community uses to identify meaningful, productive, and high quality engagement?
5. When should touch points with the communities occur throughout the project lifespan and how do they relate to assessing success?
6. Are there standard tools researchers could use to measure community engagement to enable comparative analysis?
7. What tools or formal opportunities are there for communities to both set measures of success and to provide assessment of partnerships with researchers? When these assessments are done are they more so for the internal team or is their value in sharing outcomes more broadly (i.e., publications, annual reports)?
8. What types of expertise and experience is needed on the research team to ensure sustainability of the relationships with the communities?

NATIONAL ACADEMIES Sciences Engineering Medicine

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

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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**.

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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

Workshop Session I: Opening Remarks & Keynote Address

- Doerr, Megan, and Joon-Ho Yu. "Translational research and communities." *Ethics & Human Research* 45.5 (2023): 34-38. https://pubmed.ncbi.nlm.nih.gov/37777978/
- Lemke, Amy A., et al. "Assessing Vietnamese American patient perspectives on population genetic testing in primary care: a community-engaged approach." *Human Genetics and Genomics Advances* 3.4 (2022). https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9418978/
- The Power of Community at Nemours Children's Health (2024) https://blog.nemours.org/2024/05/the-power_of_community_at_nemours_childrens_health/
- Beans, Julie A., et al. "Community protections in American Indian and Alaska Native participatory research—A scoping review." Social Sciences 8.4 (2019): 127. https://www.mdpi.com/2076-0760/8/4/127
- 23andMe and Sickle Cell 101 Collaborate to Expand Sickle Cell Awareness Program https://www.globenewswire.com/news-release/2023/09/14/2743122/0/en/23andMe-and-Sickle-Cell-101-Collaborate-to-Expand-Sickle-Cell-Awareness-Program.html
- Roth, Sarah, et al. 2024. Experiences of hereditary cancer care among transgender and gender diverse people: "It's gender. It's cancer risk… it's everything." *Journal of Genetic Counseling.* https://pubmed.ncbi.nlm.nih.gov/38342966/
- DNA Dialogues podcast episode: #4 Discussing Gender Inclusive Terminology and Gender-Affirming Hereditary Cancer Care https://dnadialogues.podbean.com/e/4-discussing-gender-inclusive-terminology-and-gender-affirming-hereditary-cancer-care/

Workshop Session II: Challenges and Opportunities for Sustaining Community Engagement and Partnerships in Genomics Research

- Personal Experience Motivates Dr. Lametra Scott's Work to Raise Awareness of Sickle Cell https://blog.23andme.com/articles/sickle-cell-awareness
- https://pubmed.ncbi.nlm.nih.gov/33984519/
- Bland, Harris T., et al. "Conducting inclusive research in genetics for transgender, gender-diverse, and sex-diverse individuals: Case analyses and recommendations from a clinical genomics study." *Journal of Genetic Counseling* (2023). https://pubmed.ncbi.nlm.nih.gov/37667436/

- Clayton, Ellen Wright, Harris T. Blank, & Kathleen F. Mittendorf. “Protecting Privacy of Pregnant and LGBTQ+ Research Participants.” *JAMA* (2024). https://jamanetwork.com/journals/jama/fullarticle/2817544
- Mittendorf, Kate F., et al. "Cancer Health Assessments Reaching Many (CHARM): a clinical trial assessing a multimodal cancer genetics services delivery program and its impact on diverse populations." *Contemporary clinical trials* 106 (2021): 106432. https://pubmed.ncbi.nlm.nih.gov/33984519/.
- Claw, Katrina G., et al. "A framework for enhancing ethical genomic research with Indigenous communities." *Nature communications* 9.1 (2018): 2957. https://www.nature.com/articles/s41467-018-05188-3

Workshop Session III: Methodologies to Sustaining Community Engagement and Partnerships in Genomics Research

- Tindana, Paulina, et al. "Community engagement strategies for genomic studies in Africa: a review of the literature." *BMC medical ethics* 16 (2015): 1-12. https://bmcmedethics.biomedcentral.com/articles/10.1186/s12910-015-0014-z
- Kisiangani, Isaac, et al. "Perspectives on returning individual and aggregate genomic research results to study participants and communities in Kenya: a qualitative study." *BMC Medical Ethics* 23.1 (2022): 27. https://link.springer.com/article/10.1186/s12910-022-00767-y
- Deliberative Community Engagement as Tool for Understanding Genetic Screening https://precisionhealth.uahs.arizona.edu/event/deliberative-community-engagement-tool-understanding-genetic-screening
- Jarvik, Gail P., et al. "Return of genomic results to research participants: the floor, the ceiling, and the choices in between." *The American Journal of Human Genetics* 94.6 (2014): 818-826. https://www.cell.com/ajhg/pdf/S0002-9297(14)00181-5.pdf
- Lunn, Mitchell R., et al. "A digital health research platform for community engagement, recruitment, and retention of sexual and gender minority adults in a national longitudinal cohort study−−The PRIDE Study." *Journal of the American Medical Informatics Association* 26.8-9 (2019): 737-748. https://academic.oup.com/jamia/article/26/8-9/737/5509461

Workshop Session IV: Measuring and Assessing Community Engagement and Partnerships in Genomics Research

- NAM Assessing Meaningful Community Engagement https://nam.edu/programs/value-science-driven-health-care/assessing-meaningful-community-engagement/

- Akintobi, Tabia Henry, et al. "Processes and outcomes of a community-based participatory research-driven health needs assessment: a tool for moving health disparity reporting to evidence-based action." in community health partnerships: research, education, and action 12.1 Suppl (2018): 139. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5977395/pdf/nihms968176.pdf
- Watson, Karriem S., et al. "Adapting a conceptual framework to engage diverse stakeholders in genomic/precision medicine research." *Health Expectations* 25.4 (2022): 1478-1485. https://onlinelibrary.wiley.com/doi/full/10.1111/hex.13486