

# 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.

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

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*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 genomic research projects. Touch on how engagement and partnership is or is not different for a genomics study.

## Sustaining Community Engagement in Genomics Research: A Workshop

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 Sickle 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

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*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

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*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

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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*  
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