

Sustaining Community Engagement in Genomics Research: A Workshop

Kellan Baker, Workshop Co-Chair

Sandra Soo-Jin Lee, Workshop Co-Chair

JULY 17, 2024

Planning Committee Members

Kellan Baker (*workshop co-chair*), Whitman-Walker Institute

Sandra Soo-Jin Lee (*workshop co-chair*), Columbia University

Natasha Bonhomme, Genetic Alliance, Expecting Health

Yue Guan, Rollins School of Public Health, Emory University

Vanessa Hiratsuka, Southcentral Foundation, National Resource Center for Alaska Native Elders (NRC-ANE)

Amy Lemke, University of Louisville, Norton Children's Research Institute

Sheri Schully, All of Us Research Program, NIH

Joyce Tung, 23andMe, Inc.

Joseph Yracheta, Native BioData Consortium

Goals of the Workshop

- 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).

Scope for this Workshop

Sustained community engagement as

- a way to not only improve research, but also equally benefit communities.
- long-term partnerships.
- taking the time to understand a community, or nation, and their language (and in some cases needing to understand the rules that govern a population and how those laws apply to those who seek to work with them).
- occurring in both U.S. and international contexts
- equitable sharing of resources between researchers and the communities.

Agenda



- Session I: Opening Remarks & Keynote
- Session II: Challenges and Opportunities for Sustaining Community Engagement and Partnerships in Genomics Research
- Session III: Methodologies to Sustaining Community Engagement and Partnerships in Genomics Research
- Session IV: Measuring and Assessing Community Engagement and Partnerships in Genomics Research
- Session V: Final Reflections

Best Practices for Participating

In-Person

- To ask a question, speak into a microphone and state your name and affiliation first
- Please be present and engaged
 - e.g., limit distractions and use of other devices in the room not related to the meeting

Remote

- Use the Slido box under the webcast to share your questions for the panelists
- Please be present and engaged

Reminders

- Detailed speaker bios can be found on page 22 of the briefing book located on the workshop webpage
- We have a full agenda and will be strict with keeping to the scheduled time for talks
- A survey will be shared with you after the workshop to collect your feedback
- The videos from the workshop will be posted to the workshop website within a couple of weeks
- A Proceedings–in Brief from this workshop will be released later this year to capture the discussions
- Thank you for joining us!

Session I: Opening Remarks and Keynote



Scan the QR code to access
the closed captioning on your
personal device