Workshop report: Future Directions in Genomics and Health Equity

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National Advisory Council for Human Genome Research
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Future Directions in Genomics and Health Equity
Research Virtual Workshop

- Workshop Goal: Identify research gaps and opportunities that will help address health disparities and improve health equity in genomics
- Over 300 participants
- Co-chairs: Judy Cho, Icahn School of Medicine at Mount Sinai; Sandra Soo-Jin Lee, Columbia University
Keynote speakers

Setting the Stage: A Vision for Health Equity in Genomics
• Nancy Cox, Vanderbilt University

Current Research in Genomics and Health Equity
• John Carpten, University of Southern California

Current Challenges in Genomic Research and Genomic Medicine That Lead to Health Disparities
• James Hildreth, Meharry Medical College
• Genevieve Wojcik, John Hopkins University
Moving Forward: From Health Disparities to Health Equity in Genomics

Panelists:
• Esteban Burchard, University of California, San Francisco
• Vanessa Hiratsuka, University of Alaska Anchorage
• Latrice Landry, Harvard University
• Maya Sabatello, Columbia University

Moderator:
• Eliseo Pérez-Stable, National Institute on Minority Health and Health Disparities
Identifying Research Gaps and Opportunities

Panelists:
• Rick Kittles, City of Hope
• Loren Saulsberry, University of Chicago
• Michael Inouye, University of Cambridge

Moderator:
• Chanita Hughes-Halbert, University of Southern California
Addressing Structural Factors Needed to Support Health Equity Research in Genomics

Panelists:
• Kellan Baker, Whitman-Walker Institute
• Rene Begay, University of Colorado Anschutz Medical Campus
• Faith Fletcher, Baylor College of Medicine
• Neil Risch, University of California, San Francisco

Moderator:
• Carol Horowitz, Mount Sinai School of Medicine
## Breakout Groups (open to all registrants)

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<th>Breakout Group</th>
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<td>• Tabia Henry Akintobi, Morehouse School of Medicine</td>
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<td>• Nanibaa’ Garrison, University of California, Los Angeles</td>
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<td><strong>Structural Factors</strong></td>
<td>• Nita A.Limdi, University of Alabama at Birmingham</td>
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<td>• Stephanie Malia Fullerton, University of Washington</td>
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<td><strong>From Bench to Bedside: The Implementation Science of Genomics and Health Equity</strong></td>
<td>• Denise Dillard, Southcentral Foundation, Alaska</td>
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<td>• Elizabeth Ofili, Morehouse School of Medicine</td>
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<td><strong>Data Science Genomics Equity</strong></td>
<td>• Valentina Di Francesco, National Human Genome Research Institute</td>
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<td>• Jeff Leek, John Hopkins School of Public Health</td>
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<td><strong>Health Equity Research in ELSI</strong></td>
<td>• Catherine Hammack-Aviran, Vanderbilt University School of Medicine</td>
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<td>• Benjamin Wilfond, Seattle Children’s Hospital</td>
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Selected discussion points

- Defaulting to laboratory reference ranges based on European ancestral populations results in misdiagnoses, under- and over-treatment
- Lack of diversity in researchers, peer reviewers has far-reaching impact on what is studied
- Address lack of data re: using race or ethnicity in clinical algorithms
- Necessity to oversample recent African ancestral populations
- Evaluating downstream impacts in health equity should go beyond representation in data to include health implications
- Strengthen bi-directional relationships between researchers and community members
Opportunities for NHGRI

- Diversify the genomic workforce and landscape
- Address the lack of diverse genomic data
- Understand how lack of diversity in populations and communities comprising genomic research cohorts impacts health disparities
- Address inappropriate use of racial categories in research, laboratory values and clinical markers and underutilization of genomic markers
- Nurture long standing relationships with diverse communities to build trust and conduct research equitably
- Develop metrics of health equity, such as measures of access to genomic testing, and apply them across genomic studies
What recommendation is the most important for NHGRI to consider when developing future research opportunities in genomics and health equity?

- **29%**
  Diversify the genomics workforce by targeting HBCUs, MSIs, Tribal Colleges, and Community Colleges

- **23%**
  Ensure sufficient time, equitable resource distribution, and funding for appropriate community engagement

- **9%**
  Include a robust understanding of contextual variables and diverse settings; include health equity metrics

- **7%**
  Routinely collect data on abilities, demographics and barriers to participation, and use for process improvement

- **7%**
  Include training on and an analytic plan for collecting and using SDOH measures

- **7%**
  Require training on diversity, sensitivity and inclusion for funders; participatory role in decision-making for community members

- **6%**
  Enhance workforce diversity of clinicians and clinical teams to communicate genomic research with a health equity lens

- **6%**
  Diversify the demographic and disciplinary background of ELSI researchers

- **3%**
  Engage students earlier in the educational pipeline to interest and support students in data science

- **3%**
  Support long-term training opportunities to study underrepresented populations using SDOH measures
Health equity is broadly relevant across ALL aspects of genomics research.
Next steps


Preparation of manuscript for submission to peer-reviewed publication
Acknowledgments

- NHGRI planning committee
  - Vence Bonham
  - Lucia Hindorff
  - Amber Jackson
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  - Jennifer Troyer

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  - Mukul Nerukar
  - Jerryl Somani

- NHGRI Program Analysts
  - Madison Goldrich
  - Kathleen Renna
  - Ella Samer

- Workshop co-chairs, speakers, moderators, breakout group leaders, panelists
  - Judy Cho, Co-Chair
  - Sandra Soo-Jin Lee, Co-Chair
  - Kellan Baker
  - Rene Begay
  - Larry Brody
  - Estaban Burchard
  - Leia Butler
  - John Carpten
  - Nancy Cox
  - Denise Dillard
  - Valentina Di Francesco
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  - Karriem Watson
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  - Genevieve Wojick