Charge: This workshop will examine the use of race and ethnicity in biomedical and genomics research and how this applies to minority health and health disparities research. Workshop participants are asked to identify the complexities associated with using self-identified race and ethnicity (SIRE) and ancestry informative markers or other means of describing populations in biomedical and clinical research. Participants are asked to aid in: 1) the development and application of a framework for appropriate use of race and ethnicity in future studies, 2) identification of research questions to advance understanding of SIRE and genetic ancestry, and 3) generating a list of recommendations for how genomics and biomedical research can describe participants' diverse backgrounds and experiences in ways that are scientifically and socially meaningful.

AGENDA

Monday, October 24

8:30 am - 9:00 am Registration

9:00 am – 9:20 am **Opening Remarks**

Eric Green MD, PhD, and Eliseo J. Pérez-Stable, MD

9:20 am – 9:50 am Introductory Talk: Current Use of Self-Identified Race and Ethnicity (SIRE) and Genetic

Ancestry in Biomedical Research

Eric Boerwinkle, PhD

9:50 am - 10:00 am Break

10:00 am – 11:20 am **Topic**: The Utility of SIRE in Genomics and Biomedical Research

Moderator: Chanita Hughes-Halbert, PhD

Perspectives:

10:00 am - 10:15 am David E. Hayes-Bautista, PhD

10:15 am – 10:30 am Rick Kittles, PhD

Discussion: 10:30 am - 11:20 am

11:20 am – 12:40 pm **Topic**: The Utility of Ancestry Informative Markers in Genomics and Biomedical Research

Moderator: Joanna Mountain, PhD

Perspectives:

11:20 am – 11:35 am Esteban G. Burchard, MD, MPH

11:35 am – 11:50 am Sarah Tishkoff, PhD

Discussion: 11:50 am – 12:40 pm

12:40 pm - 1:45 pm Lunch



1:45 pm – 3:00 pm **Topic:** How Should Race and Ethnicity Be Used to Report Genetic Variation

in Research?

Moderator: Laura Fejerman, PhD

Perspectives:

1:45 pm – 2:00 pm Stephanie Malia Fullerton, PhD

2:00 pm – 2:15 pm Dorothy Roberts, JD

Discussion: 2:15 pm - 3:00 pm

3:00 pm – 3:15 pm **Break**

3:15 pm – 4:30 pm **Topic:** How Should Race and Ethnicity Be Used to Report Genetic Variation in

Non-Research Settings (including Clinical and Direct-to-Consumer testing)?

Moderator: Fernando Mendoza, MD, MPH

Perspectives:

3:15 pm – 3:30 pm
3:30 pm – 3:45 pm

Kenneth Chahine, PhD, JD
Katrina Armstrong, MD

Discussion: 3:45 pm - 4:30 pm

4:30 pm – 5:50 pm **Topic:** What is the Appropriate Use of SIRE and Ancestry Informative Markers in

Minority Health Research and Health Disparities Research?

Moderator: Sarah J. Gehlert, PhD

Perspectives:

4:30 pm – 4:45 pm *Neil Risch, PhD* 4:45 pm – 5:00 pm *Jun J. Yang, PhD*

Discussion: 5:00 pm - 5:50 pm

5:50 pm – 6:00 pm **Day One Wrap-Up**

6:00 pm Close



Tuesday, October 25

9:00 am – 9:15 am Welcome – Recap and Charge for the Day (Strategies)

9:15 am – 10:30 am Panel Presentations and Discussion: The Role of the Scientific Community in Implementing a New Conversation on Race and Ethnicity Across Disciplines

Moderator: Tesfaye Mersha, PhD

Panelist 1: Nanibaa' Garrison, PhD
 How can social science and genomics researchers better collaborate?

Panelist 2: Lucila Ohno-Machado, MD, PhD
 How should electronic health records report and use race and ethnicity in the second seco

How should electronic health records report and use race and ethnicity for research purposes?

• Panelist 3: Valda Vinson, PhD

What role can scientific journals play in moving forward consensus standard in use of race and ethnicity in genomics and minority health and health disparities research?

• Panelist 4: Aliya Saperstein, PhD

What role can the scientific community play in moving forward consensus standard in use of race and ethnicity in genomics and minority health and health disparities research?

Panelist 5: Keegan Sawyer, PhD

What role can the National Academies play in exploring the use of race and ethnicity in genomics and biomedical research?

10:30 – 10:45 am **Break**

10:45 am – 12:00 pm Consensus and Research Opportunities Discussion for First Meeting Objective

Moderator: Sharon Terry, MA

What Strategies Are Needed to Utilize Race and Ethnicity as a Variable in Clinical, Population, and Genomics Research?

12:00 pm -1:00 pm Lunch

1:00 pm - 2:20 pm Consensus and Research Opportunities Discussion for Second Meeting Objective

Moderator: Michael Yudell, PhD, MPH

What are Strategies that Address the Challenges of Using SIRE and Ancestral Background

with Genomic Information?

2:20 pm – 2:50 pm Reflections on the Workshop

Aravinda Chakravarti, PhD

2:50 pm – 3:00 pm Directors' Next Steps and Closing Remarks

3:00 pm Close



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