

Draft Agenda
ELSI Strategic Planning Webinar #2
Genomic Decision-Making: Power and Identity
July 9, 3 – 5 pm ET

The National Human Genome Research Institute (NHGRI) is undergoing a Strategic Planning process with the goal of publishing the final Strategic Plan in the fall of 2020. Over the past year, the NHGRI has held numerous related engagement [events](#) including town halls, meetings and workshops. NHGRI staff have formed internal working groups tasked with identifying and describing ambitious challenges to address in the next decade of genomics. These draft challenges, which have been informed by the feedback received to date, are meant to serve as potential building blocks for the final strategic plan which will be published in October 2020.

The internal working group that focused on ELSI, engagement and education issues in the strategic plan is hosting two distinct webinars to gather feedback on four potential challenges for the field of ELSI research over the next decade. The intent is to ask participants to think broadly about the challenges without regard to NHGRI grant mechanisms, research methods, disciplines, or funding levels. In each webinar, participants will evaluate and advise NHGRI on two related challenges.

The webinar will begin with a brief overview of the NHGRI Strategic Planning Process. Next, WebEx will be used to divide participants into one of two virtual rooms (A or B) for a discussion of the first challenge. Breaking into smaller groups will allow more people to take part in the conversation. Participants will remain in the same virtual room for discussion of the second challenge. Finally, all participants will be brought back together for a summary discussion.

Agenda:

3:00 – 3:20 pm ET	Overview of Strategic Planning Process and Feedback	Dave Kaufman
3:20 – 4:00 pm ET	Breakout Discussion 1: Empower people to make well-informed decisions about genomic data access, use, sharing and protection	Moderators: Group A: Carla Easter Group B: Nicole Lockhart
4:00 – 4:40 pm ET	Breakout Discussion 2: Track and shape genomics' influences on concepts of health and wellness, identity, family and community	Moderators: Group A: Joy Boyer Group B: Dave Kaufman
4:40 – 5:00 pm ET	Summary Discussion	All participants

Draft Discussion Questions:

I. Context and Significance

- What is already known or on the horizon that makes this goal timely?
- Why is/isn't this important?
- Why is/isn't this compelling/aspirational/forward looking?
- Is it novel?

II. Barriers

- Is the goal tractable? What are the barriers to achieving this goal? (e.g. technical, organizational, or social impediments)
- Are there critical resources that need to be developed to enable this work?

III. Is this goal forward looking? Is it appropriate for NHGRI?

- What role should NHGRI play in reaching the goal?
- Why is/isn't NHGRI suited to pursue this goal?
- Is the goal timely? Why now?

WebEx Information:

1. **Be at a computer for the webinar.** The full functionality will not be available to those who only dial in and you will miss the discussion portion of the webinar. Please email alex.rafael@nih.gov if you expect that you will be unable to be at a computer for the webinar.
2. Go to <https://nih.webex.com/nih/k2/j.php?MTID=t9a094992b44652d2fe264233ae3ee72f>
3. Enter your name and email address
4. Enter the session password: ELSI
5. Click "Join Now".
6. Follow the instructions that appear on your screen.
To view in other time zones or languages, please click the link <https://nih.webex.com/nih/k2/j.php?MTID=t21b1c7623c24d3c6b3409e4058327c07>
7. Please see the ELSI Strategic Planning WebEx User Guide for more information on how to use the WebEx Training feature