

An Overview of **Workshop Priorities**

Subhashini Chandrasekharan, PhD | *ELSI Lead*

All of Us
RESEARCH PROGRAM

The
Future of
Health Begins
With You



National Institutes
of Health

All of Us Policy Office

@AllofUsResearch #JoinAllofUs

Workshop Goals and Objectives

- Aid the program in its commitment to advance efforts to identify and assess the ethical, legal, and social implications (ELSI) of research using the *All of Us* data repository, as well as the program itself, to benefit both the program and the broader research community.
- Convene a diverse group of ELSI experts to ensure a wide variety of communities are represented.
- Provide attendees with detailed information about the *All of Us* Research Program
- Solicit feedback for improvement of the *All of Us* data resource to advance ELSI research

Workshop Goals and Objectives

- **Convene a diverse group of ELSI experts to ensure a wide variety of communities are represented**
 - ELSI experts from within and outside the program
 - Early career ELSI researchers
 - NIH and HHS Staff
 - *All of Us* Participant Ambassadors
 - *All of Us* Staff
- **Provide attendees with a deeper understanding of the All of Us Research Program**
 - Scientific roadmap
 - Current and planned data resources
 - Current and planned analytical resources

Workshop Goals and Objectives

- **Solicit feedback for improvement of the *All of Us* data resource** to advance ELSI research
- ❑ What are the **essential ELSI questions** the community would like to be able to study using *All of Us* (either its scientific resources or the program itself) as a platform?
- ❑ What **data types** do we already have, and what would we need to add to enable researchers to address these lines of inquiry?
- ❑ What additional **tools or features** would it help for us to provide?

Workshop Goals and Objectives

Facilitated activities of the break-out sessions to:

- Develop use cases to identify the strengths and weaknesses of the resources
- Identify additional data collection needs to enable ELSI research
- Identify analytical and logistical needs to enable ELSI research

Cross-cutting themes of the ELSI research workshop

While the three workshop workstreams are heavily interrelated, each will have a distinct core focus:

Genomics: the Genomics Workstream will concentrate on issues related to the design and translation of genomics research, including the return of genomic research results to participants; collecting and analyzing DNA from vulnerable or underrepresented populations; and genomic privacy.

Legal/Regulatory Policy: the Legal/Regulatory and Policy Workstream will concentrate on the influence of the legal and regulatory framework on the practice of research, including such issues as the changing privacy landscape; legal/regulatory supports for, and barriers to, evolving research agendas; and enabling evidence-based policymaking.

Social Determinants of Health: the Social Determinants of Health Workstream will concentrate on the impact of social, environmental, and other factors on health outcomes, including such topics as accurate collection of data on social and lifestyle variables; ethical considerations in the study of health disparities; and the impact of research on vulnerable populations.

Workshop outcomes

- Meeting Summary
- White paper and case-studies
- Guidance for Priority-Setting

Questions?

All of Us
RESEARCH PROGRAM

The
Future of
Health Begins
With You

joinallofus.org

@AllofUsResearch | #JoinAllofUs

aouelsi@nih.gov

Precision Medicine Initiative, PMI, All of Us, the All of Us logo, and The Future of Health Begins With You are service marks of the U.S. Department of Health and Human Services.