

WEBINAR AGENDA:

Identifying Needs and Resources to Increase the Reach, Impact and Transparency of ELSI Research

The Ethical, Legal and Social Implications (ELSI) Research Program will host two webinars in the next few weeks to gather ideas from the research community on needs and resources to increase the reach, impact, and transparency of ELSI research. These webinars follow on the heels of the 2017 ELSI Congress and the launch of a new stage of strategic planning at the National Human Genome Research Institute (NHGRI).

There are four major topics on which we would like to gather perspectives. First, despite the broad applicability of ELSI research to many areas of clinical and biomedical research, ELSI findings and publications are often less known and utilized outside of genomics. We do not always succeed in putting ELSI work in the hands of those who can use it. Second, it can be difficult to establish the rigor and reproducibility of data, compare findings or conduct cross-study analyses if measures and instruments are not publicly available. Third, there is currently no systematic way of synthesizing and/or disseminating ELSI findings across studies. This is particularly difficult given the multidisciplinary nature of ELSI work. Finally, dialogues on current topics often seem uninformed by previous foundational research. For example, many issues arising out of the use of gene editing technologies were explored, at least in part, more than a decade ago, but that foundational scholarship is seldom drawn upon by those entering the field. This webinar will provide an opportunity for attendees to provide feedback and input to NHGRI staff on these and other challenges facing the ELSI research community.

Agenda:

20 min – Introduction

20 min – Discussion: Increasing the reach, impact, and transparency of ELSI research

- Is there a need to better coordinate, synthesize and/or translate ELSI research findings? If yes, how could this be accomplished most effectively and efficiently? Are there examples of particularly successful efforts and/or missed opportunities?
- As genomics moves into more disease areas, how can we help ensure that the ELSI research funded by NHGRI is considered and various “lessons learned” are incorporated elsewhere? How can we extend the reach of work we are already funding?
- In the next 10 years as technology and research evolve, which areas of biomedicine or policy development will have the greatest need for ELSI research? What research topics or foci will be of most use?

40 min – Discussion: Needs and resources

- Is there a need to promote more sharing of tools, measures, instruments, and resources in the ELSI community? What about sharing data?
- Would critical methods analyses, meta analyses, or literature reviews be useful? Are there specific areas where such work could have the greatest impact?
- How do we promote effective, timely responses to issues as they arise in media and the government? How could NHGRI facilitate such efforts?
- Other needs appropriate for NHGRI and/or the ELSI Research Program?

10 min – Summary and closing remarks