

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

## March 13 and 26, 2018

### Overview:

NHGRI recently initiated a [new round of planning](#), which will result in an updated strategic plan published in 2020. To inform this strategic planning, the NHGRI ELSI Research Program hosted two public webinars to gather ELSI researchers' ideas on approaches and resources that would increase the reach, impact, and transparency of ELSI research. Participants discussed how to deliver ELSI research to the widening range of stakeholder groups to increase the efficiency of research, as well as how to establish the rigor and reproducibility of data, compare findings and conduct cross-study analyses in ELSI research.

Nicole Lockhart presented an introduction, followed by a discussion facilitated by David Kaufman and Joy Boyer. NHGRI staff noted that these webinars were only the first of several upcoming opportunities for community feedback on the strategic plan; participants were also encouraged to submit additional feedback by email.

### Thematic Summary of the March 13 and March 26 Webinar Discussions:

#### *Reflections on the Visibility of ELSI Research*

Participants observed that researchers outside of genomics find it difficult to identify existing ELSI research and proposed numerous reasons why this is so. For example, the diversity of ELSI research disciplines and methodologies, while a strength of the field, leads to publications in hundreds of different and diverse journals. This can make it difficult to track the full range of ELSI publications. Additionally, many ELSI journals are not indexed in a central database, producing barriers for researchers looking for research, tools, and measures.

Webinar participants proposed numerous mechanisms for increasing the visibility and uptake of ELSI research, including a newsletter that summarizes recent findings, special journal issues focused on ELSI topics, or formal white papers/professional guidelines to introduce naïve readers to ELSI topics and facilitate the discovery of primary ELSI literature. Participants were particularly interested in meta-analyses and literature reviews, though they recognized a diverse team of authors would be needed to cover the methodological breadth of the field.

Other participants noted another consequence of this visibility issue. In many areas where genomics is just developing, new groups of researchers and clinicians are becoming aware of well-studied issues like informed consent or the return of results, but are unaware of the large body of ELSI scholarship already available to them. This might lead to inefficient or redundant research.

On the other hand, participants on the calls also noted that some ELSI research needs to be periodically repeated to capture changing social contexts and cultural mores. Therefore, concerns about repeated ELSI research should be tempered by an expectation that ELSI research may require more repetitions over time than traditional biomedical research, where new research builds linearly on existing findings once reproducibility has been assessed.

### *Sharing instruments, measures, and data*

Participants discussed whether increased sharing of instruments, measures, and primary data would help increase the accessibility and efficiency of current ELSI research.

Participants were enthusiastic about sharing instruments and tools. Some noted that tools are expensive and time-intensive to develop and validate. Increasing the sharing of these measures would increase research efficiency. Participants proposed that a central location for sharing instruments and measures would promote equity of access, particularly for trainees and new investigators.

However, the group did not reach a consensus about whether to increase ELSI data sharing. Those in favor felt that access to primary data would encourage the rigor and reproducibility of ELSI data and increase the number of secondary analysis research projects. While they recognized the ethical concerns of data sharing, particularly of qualitative data, these participants felt that responsible data sharing standards could be developed for ELSI research data. Due to the heterogeneous nature of ELSI research, participants felt that any data sharing efforts would need to be prospective and centrally coordinated.

Other participants cited concerns about the potential utility of publicly accessible ELSI data. Numerous participants highlighted the importance of the context of ELSI data, and that this context is not easily captured in a database. Concerns also focused on the challenge of anonymizing and standardizing data, particularly qualitative data. Some participants felt that increased data sharing would not substantially benefit the ELSI community and that other steps, like encouraging the pre-registration of proposed research plans and data analyses or developing a central resource for training ELSI researchers in study design, would help to address reproducibility and encourage interdisciplinary work.

### *Increasing communication with stakeholders*

Many participants commented on the need to increase communication with stakeholders, including genomic scientists, genomic health care professionals, and policy-makers. Participants said that translating appropriate ELSI research into professional guidelines could provide resources to external researchers and practitioners. To this end, participants proposed NHGRI promotion of collaborations with relevant professional societies and other NIH Institutes and Centers with a genomic research portfolio. Targeted workshops hosting interdisciplinary attendees to address a single ELSI research topic were also proposed.

Participants were interested in finding ways of developing effective and timely responses to emerging issues. They stressed the need to balance the thoughtfulness of an academic approach with a more rapid turn-around than a traditional grant cycle. Participants provided several suggestions for reaching out to the media, including an academic blog for connecting completed research to emerging news stories. Some participants proposed a mechanism, similar to the American Sociological Association's [Find an Expert](#) tool, for individuals to volunteer as a media contact for an area of research.

### *Funding and the impact on ELSI research*

The researchers noted that, beyond NHGRI's congressionally mandated research funds, a trans-NIH commitment to bioethics scholarship has helped broaden ELSI research to address other fields. Webinar participants were particularly supportive of funding announcements focused on

ELSI in a broader context, including NOT-LM-17-001 (“Notice of Interest in High Priority Research in Bioethical, Legal, and Societal Implications of Biomedical Research”).

Participants felt there were emerging ELSI issues in numerous fields, including Alzheimer’s disease research, transplant medicine, “Big Data” and artificial intelligence, and innovative/disruptive technologies (i.e. CRISPR/Cas9). The researchers proposed numerous ways of funding work to address these issues, particularly through embedded ELSI projects that are a specific aim of a larger, biomedical research project or clinical trial, but they noted previous projects of this nature have faced barriers due to limited funding support or relatively small budgets.

### *Conclusion*

NHGRI is appreciative of all the feedback offered by the ELSI community. The opinions and suggestions offered will be considered as NHGRI analyzes the strategic approaches for reaching the “Forefront of Genomics.” NHGRI staff welcomes any additional opinions, suggestions, or questions, which can be submitted to [elsi@mail.nih.gov](mailto:elsi@mail.nih.gov)