

# Welcome to the ELSI Webinar!

To maximize participation and keep things running smoothly:

- You will be muted during the intro presentation
- Please sign into WebEx with your full name
- Please turn off your webcam – too many participants for video
- We will try unmuting everyone during the discussion
- Use WebEx features like “raising your hand” (next to your name) or entering a question/comment into the chatbox
- Email additional questions or comments to: [elsi@mail.nih.gov](mailto:elsi@mail.nih.gov)
- We are recording this webinar to help produce an executive summary. We will not distribute or post the recording.

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

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National Human Genome  
Research Institute

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The **Forefront**  
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# What we're trying to accomplish today

- Gather ideas from the ELSI research community on needs and resources to increase the reach, impact, accessibility and transparency of ELSI research
- Will start off with a brief intro to the NHGRI and the ELSI Research Program
- Followed by two general areas of discussion with corresponding questions



# — Establishing a 2020 Vision for Genomics

<https://www.genome.gov/genomics2020/>

# ELSI Research Program: Background

- Established in 1990
- Mission: To anticipate and address the ethical, legal, and social implications of genetic and genomic research
- 5% NHGRI extramural budget set-aside
- FY2017 budget = ~\$19.5 M

# Current ELSI Research Domains

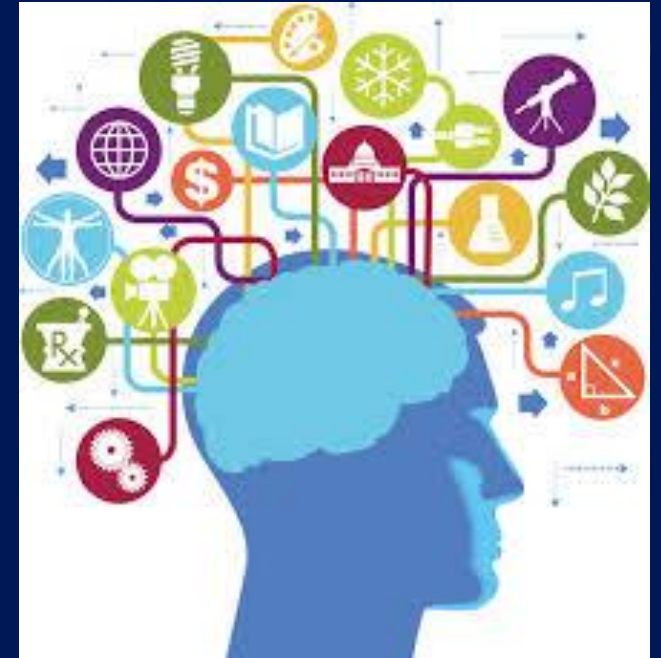
- Genetic and Genomic Research
- Genetic and Genomic Healthcare
- Broader Legal, Policy and Societal Issues

*Detailed descriptions available at:*

<https://www.genome.gov/27543732/elsi-research-domains/>

# Selected Disciplines of ELSI Applicants

- Bioethics and Ethics
- Biomedical and Behavioral Sciences
  - e.g. Genetics, Biology, Neuroscience, Pharmacology
- Humanities
  - e.g. History, Philosophy, Religion/ Theology
- Law
- Medicine
  - e.g. Clinical Genetics, Nursing, Genetic Counseling, Pediatrics, Oncology, Psychiatry
- Public Health
  - e.g. Epidemiology, Biostatistics, Health Services, Population Health
- Public Policy
- Social Sciences
  - e.g. Anthropology, Economics, Political Science, Psychology, Sociology



# Wide Range of Methods in ELSI Research

- Archival research
- Community based research
- Conceptual/Critical
- Content analysis
- Discrete choice analysis
- Economic analyses
- Ethnography
- Focus groups
- Legal analysis
- Mathematical modeling
- Network analysis
- Oral history
- Quasi-experimental and experimental trials
- Stakeholder engagement
- Structured interviews
- Survey methods
- Textual interpretation
- Time series analyses





# GENOMICS AND SOCIETY

Expanding The ELSI Universe - #ELSICON

## EXPANDING THE ELSI UNIVERSE

The 4th ELSI Congress – Plenary Videos Below

Farmington, CT • June 5-7, 2017

The 4<sup>th</sup> ELSI Congress was the latest in a series of major conferences for researchers and others interested in the ethical, legal and social implications (ELSI) of genomic research.

Co-Sponsored by:



National Human Genome  
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# Access Challenges

- Despite broad applicability, ELSI findings are often less known and used outside of genomics
- Implementation and policy relevance may be under-realized
- Experts often not known to decisionmakers, media
- No established means of sharing research, tools and products
- No society or single meeting outside ELSI Congress

# Analytical Challenges

- Methods often not assessed by the field
- Breadth of methods make cross-study analyses hard- no systematic way of synthesizing ELSI findings across studies from different disciplines, using various methods
- Harder to establish rigor or reproducibility when measures and instruments are not publicly available

# Discussion: how to provide your input

- **Speak up!** If you're having a hard time getting a word in, "raise your hand" on the WebEx and we'll call on you
- Please state your name when speaking
- Use the "chat box" feature on WebEx to enter a question or comment. Send to "everyone" OR "ELSI Team"
- Questions or additional feedback can be emailed to: [elsi@mail.nih.gov](mailto:elsi@mail.nih.gov) Please provide your input by March 30<sup>th</sup>
- We are now taking everyone off mute. **Please use the mute button on your phone unless you are speaking.**

# Discussion 1: 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?

# Discussion 1: Increasing the reach, impact, and transparency of ELSI research

- 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?

# Discussion 1: Increasing the reach, impact, and transparency of ELSI research

- 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?

# Discussion 2: 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?





# Discussion 2: Needs and Resources

- Would critical methods analyses, meta analyses, or literature reviews be useful?
- Are there specific areas where such work could have the greatest impact?



# Discussion 2: Needs and Resources

- How do we promote effective, timely responses to issues as they arise in media and the government?
- How could NHGRI facilitate such efforts?



# Closing Remarks

- Other needs appropriate for NHGRI and/or ELSI Research Program?
- Additional comments may be submitted to [elsi@mail.nih.gov](mailto:elsi@mail.nih.gov) by March 30<sup>th</sup>.
- Slides and a combined executive summary from both webinars will be posted on the ELSI webpage

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# Thank you!





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