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Concept Clearance: Center for ELSI Resources & Analysis (CERA)

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ELSI Research Challenges: Access

- Despite broad applicability, ELSI findings often less known and used outside NHGRI sphere of influence
- Implementation and policy relevance may be under-realized
- Diverse work - widely dispersed
- No established means of sharing research, methods and products
- No society or single meeting outside ELSI Congress

ELSI Research Challenges: Analytical

- Broad range of methods and disciplines
- Systematic synthesis could serve as the “state of the field”
- More methods assessment to improve rigor and study design
- Publicly available measures and instruments would improve rigor, reproducibility, efficiency and access

ELSI Research Community Webinars

- Hosted 2 webinars in March 2018 with 80 participants
- Support for increased collaboration between researchers in ELSI, genomics, and other biomedical and clinical areas
- Support for sharing of instruments, measures and tools
- Mixed opinions on sharing ELSI data, especially qualitative
- Support for summarizing and conducting meta-analyses

Purpose

The Center for ELSI Resources and Analysis will:

1. Provide ELSI researchers with an established platform to share their research tools and products related to genomics;
2. Serve as a resource for curating and synthesizing research on key topics in the field, highlighting new findings and providing access to these works
3. Convene ELSI researchers for both small and larger scale transdisciplinary projects and meetings to develop a more synergistic and integrated ELSI research community

1 - Resource Sharing and Coordination

- Collect, index, store, and make available ELSI research instruments and methods
- Maintain a central database of ELSI scholarship and products
- Identify research tools and products for inclusion
- Collect and coordinate information on how to access data from NHGRI-funded ELSI studies
- Conduct usability testing and evaluation to assess ongoing needs
- Ensure resources and tools are portable and transferrable

2- Data Integration, Synthesis and Translation

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- Summarize ELSI scholarship via meta-analysis and literature review
- Identify areas of consensus, disagreement, and research gaps
- Conduct or organize methods assessments to improve rigor and reproducibility



3- Meeting Organization and Coordination

- Plan and execute biennial ELSI Congress
- Organize topic-centered webinars, workshops or meetings generating scholarship
- Facilitate ELSI scholars' responses to current and emerging issues

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Outreach and Engagement Plan

- Encourage and incentivize participation in the Center
- Connect ELSI researchers
- Ensure that genomic researchers, practitioners, trainees, funders, and policy makers are aware of relevant NHGRI-funded work
- Inform the ELSI community about the expanding genomic landscape

Scope

- ELSI research related to genetics and genomics
- Will provide broad access to tools and products
- Regular input provided by an External Scientific Panel with diverse expertise
- External Scientific Panel will assess milestones and ensure needs considered in an inclusive and unbiased manner

Relationship to Ongoing Activities

- Bring together ELSI research tools and products and add value by synthesizing research
- Provide more equitable access for researchers
- Increase the availability and visibility of ELSI resources
- Key convener and source of expertise
- Would not replace existing Coordinating Centers, but would provide a central ELSI resource

Mechanism and Funding

- U24 award starting in FY19
- Up to \$6M total costs over 5 years
- Total annual costs not to exceed \$1.5 M/year
- Annual budget for the first two years less than in later years
- Consulting with other Institutes/Centers about interest and/or co-funding

Thank you!

- Joy Boyer
- Larry Brody
- Erin Currey
- Maggie Ginoza
- Dave Kaufman
- Genomics and Society Working Group
- 80+ Webinar participants



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