

National Advisory Council for Human Genome Research
February 12, 2024
Concept Clearance for RFA
Ethical, Legal and Social Implications (ELSI) Congress

Purpose:

The National Human Genome Research Institute (NHGRI) proposes a Request for Applications (RFA) to renew the support of the biennial research conference of the Ethical, Legal and Social Implications (ELSI) Research Community (referred to as the “ELSI Congress”). The proposed conference will: 1) provide the multidisciplinary ELSI research community with a dedicated conference to come together and share research findings; 2) encourage collaboration across the ELSI research community with particular attention to trainees and early career scholars; and 3) provide a highly accessible format to ensure participation from a broad range of groups interested in ELSI research.

Background:

Since its founding in 1990, the NHGRI ELSI Research Program has supported empirical, analytical and conceptual research to anticipate and address the ELSI of genetics and genomics. This broad focus has created a large, diverse, and multi-disciplinary community of researchers. As a result, there is no single society or conference that encompasses the field of ELSI research.

To address this need, the NHGRI has periodically sponsored a conference to bring together those interested in ELSI research, known as the ELSI Congress. This multi-day conference with national and international representation affords ELSI researchers the opportunity to present their work and keep abreast of current research in the field. Typically, the ELSI Congress accommodates 300 to 400 attendees and includes plenary presentations, concurrent platform presentations that are peer reviewed, and dedicated sessions for trainees and early scholars that support networking and career development.

The most recent ELSI Congresses were supported by a U13 award and held virtually in 2020 and 2022 due to the COVID-19 pandemic. The two virtual conferences were widely attended and included a higher number of international attendees than in previous Congresses. For example, the 2022 virtual ELSI Congress was attended by 596 individual attendees, which was approximately twice the number of attendees from prior in-person ELSI Congresses. In addition, in 2022 abstracts were accepted from 63 institutions in 25 states across the United States and 13 institutions across 10 countries. The virtual format and lack of registration fees promoted broader and more equitable attendance. The virtual format enabled recording and archiving of presentations on the [Center for ELSI Resources and Analysis \(CERA\)](#) platform as an enduring record of the content from these conferences. In June 2024 a hybrid conference will be held in New York City as the final conference organized under the current U13 award.

Proposed Scope and Objectives:

This renewal will support three ELSI Congresses, to be held biennially. The awardee will be responsible for site selection, securing appropriate venues, conference publicity, and archiving presentations. The awardee will work with site hosts and vendors before and during the conference, arrange for AV needs, register attendees, arrange travel for plenary speakers, prepare conference materials, and conduct a post-conference survey of attendees. In addition, the awardee will develop a robust process for invitation, submission, review, and selection of abstracts as part of the conference programming process.

The awardee will work in consultation with NHGRI ELSI Research Program staff to form an organizing committee with representation from across the ELSI research community. The

ELSI Congress Organizing Committee will identify one or more themes for the Congress; design the program; and identify and invite plenary speakers. The awardee will also publicize the conference and invite submissions to ensure broad participation in the conference including among international ELSI researchers, researchers conducting ELSI-relevant work in NIH and NHGRI consortia and others who are interested, regardless of whether they receive funding from the NHGRI ELSI Research Program or self-identify as ELSI researchers. The conference is anticipated to comprise a mix of invited plenary lectures and submitted individual presentations, panel sessions, lightning talks, and poster sessions, but may involve other innovative components as well. The ELSI Congress Organizing Committee will include early career scholars to ensure the conference is responsive to career development needs. The awardee will constitute a Program Review Working Group, with additional members, if necessary, to peer review abstract submissions. The awardee will also develop a process for review of travel award applications from trainees, researchers from under-resourced institutions and/or researchers from low- and middle-income countries.

The ELSI Research Program is committed to ensuring the ELSI Congress is broadly accessible. All NIH sponsored and/or supported conferences must be held at accessible sites, as outlined by section 504 of the Rehabilitation Act of 1973 and, as applicable, the Americans with Disabilities Act of 1990. Conference registration materials should provide a questionnaire that will allow participants with disabilities to voluntarily identify any special needs, so that the conference awardee can make plans to accommodate these needs. NHGRI encourages the conference awardee to consider additional means of maximizing the accessibility of the ELSI Congress for people with disabilities including, but not limited to, real-time captioning, accessible slides and other materials provided in advance, adequate spacing for mobility aids, and conference formats that enable the use of assistive technologies and other support. The conference awardee will describe how they will facilitate broad attendance through the use of in-person and virtual content to maximize participation and allow attendance by individuals who may be unable to attend in person due to limited travel funds, disabilities, medical concerns, family obligations, or other circumstances.

NIH is committed to supporting inclusion of groups who are underrepresented in the U.S. research enterprise. Per the NIH Notice of Interest in Diversity [NOT-OD-20-031](#), underrepresented groups include individuals from nationally (US) underrepresented racial and ethnic groups, individuals with disabilities, individuals from disadvantaged backgrounds, and women. The ELSI Congress awardee will develop a plan to enhance diversity in all aspects of conference planning and implementation. The NHGRI recognizes that the value of a conference is enhanced when persons from various backgrounds, locales and perspectives are included in all aspects of conference planning and when attendees are assured of a safe, respectful, and inclusive environment free from discrimination, harassment, and other barriers that might prevent or inhibit one's participation. NIH is also committed to changing the culture of science to end sexual harassment and other forms of harassment, including harassment on the basis of race, color, national origin, sex/gender, disability, and age in NIH-funded activities. As stated in [NOT-OD-15-152](#), it is expected that the ELSI Congress awardee will take steps to maintain a safe and respectful environment for all attendees by providing an environment free from all forms of discrimination and harassment, sexual or otherwise. The ELSI Congress awardee will develop and employ strategies and policies that seek to prevent or mitigate the effects of discrimination and harassment, sexual and otherwise.

Conference planning will include development of a robust plan for how the research presented at the Congress will be preserved and disseminated. Dissemination approaches

could include posting of conference content on publicly accessible platforms including abstracts, posters, recordings, and resources; development of a special issue in a relevant journal; or other approaches.

Relationship to Ongoing Activities:

The ELSI Congress will be advertised broadly to current and former ELSI grantees from investigator-initiated programs and institutional training programs; and scholars involved in other NIH and NHGRI consortia performing ELSI-relevant research, including but not limited to the Native American Research Centers for Health and relevant international programs such as Global Alliance for Genomics & Health (GA4GH), Human Health & Heredity in Africa (H3Africa), Data Science for Health Discovery and Innovation in Africa (DS-I Africa) and programs supported by the Fogarty International Center. The ELSI Congress is an open conference for all researchers interested in examining ELSI regardless of whether they receive funding from the NHGRI ELSI Research Program or self-identify as ELSI researchers. The ELSI Congress awardee will collaborate with relevant programs such as the CERA to publicize and disseminate information about and outcomes from the conference. While the CERA does periodically organize seminars and workshops, the ELSI Congress is beyond the scope of the CERA award. However, the CERA does have a broad goal of facilitating new research collaborations and increasing uptake of ELSI research through outreach and dissemination activities which would allow for collaboration with the ELSI Congress awardee.

Mechanism of Support:

This renewal is anticipated to use the U13 mechanism of support. The planned duration of support is up to 5 years starting in FY 2025.

Funds Anticipated:

NHGRI anticipates a single award for 5 years to enable the hosting of 3 conferences. The maximum direct costs in years where a conference is held will be \$350,000.