

Frequently Asked Questions - ELSI Publications Database

How do we determine which publications are included in the database?

The database includes English-language materials on the ethical, legal, and social implications of genetics and genomics and related life sciences. As we are defining it, ELSI research includes materials that have a genetics or genomics component and an ethical, legal, and/or social implications component.

How does the CERA populate the ELSI Publications Database?

CERA staff add ELSI publications as they appear in weekly PubMed and APA PsychNet email alerts and scan the following popular ELSI journals for relevant content monthly:

- *Genetics in Medicine*
- *Journal of Law, Medicine & Ethics*
- *American Journal of Bioethics*
- *AJOB Empirical Bioethics*
- *Journal of Empirical Research on Human Research Ethics*
- *Public Health Genomics*
- *Pediatrics*
- *Journal of Genetic Counseling*
- *Journal of the American Medical Informatics Association*
- *American Journal of Medical Genetics*
- *Hastings Center Report*
- *American Journal of Human Genetics*
- *Ethics & Human Research*
- *The European Journal of Human Genetics*
- *New England Journal of Medicine*
- *Journal of Law and the Biosciences*
- *Journal of Law, Medicine & Ethics*

Our journal list includes the most frequently occurring journal titles in the [NHGRI ELSI Research Program Publications and Products database](#). To ensure inclusive coverage, we also augmented the list with journal suggestions from law and biosecurity focused ELSI scholars.

In addition to works sourced by CERA staff each month from the journal list, the database includes publications and products funded by the ELSI Research Program of the National Human Genome Research Institute (NHGRI); selections from the GenETHX: Genetics and Ethics database created by the Bioethics Research Library, Georgetown University; the ELSI Archives, curated by the Center for Genetic Research Ethics and Law, Case Western Reserve University; relevant items from the retrospective of the DOE ELSI program, prepared by Daniel Drell, then manager of the ELSI component of the DOE Human Genome Program, and Anne Adamson, then of Human Genome Management Information System (HGMS); and publications curated by the guest editors of [ELSIhub Collections](#).

We welcome submissions of published articles from the ELSI community to info@elsihub.org.

How do I submit my published article to be included in the database?

A submission form is under production, but in the meantime, please send the citation of your publication to info@elsihub.org.

How do we determine which publications to promote to the ELSI community?

CERA staff selects recently published articles to feature in the New Publications section of ELSIhub and the CERA [Twitter](#) account. We choose items that are of interest to a general audience, offer novel findings or new perspectives on well-studied issues, and/or shine a light on emerging or understudied issues. We review these items for potential conflicts of interest that could introduce bias and make an effort to highlight a broad range of institutions and research groups.

Is the ELSI Publications database comprehensive of all ELSI scholarship?

We make every effort to ensure that the database includes all ELSI scholarship reported to the ELSI Research Program of the National Human Genome Research Institute (NHGRI) as the product of an ELSI grant. Because empirical scholarship is overrepresented in the portfolio of the ELSI Research Program, it is likely that our strategy misses some normative, legal, and conceptual works. Given the lack of a central reporting mechanism for these works and their location in a variety of discipline-specific repositories, their exact number is unknown. We attempt to source unfunded works using the hand search and acquisition methods described above; however, given the

scope of this challenge, it is unlikely that our database is comprehensive of all ELSI scholarship.

What content types and date range does the database cover?

The database includes journal articles, book chapters, books, conference proceedings, reports, documents, videos, and websites authored from 1990 (the birth of the ELSI Research Program at NHGRI) through the present.

How frequently is the database updated?

The database is systematically updated monthly and on an ad hoc basis.