



Published in final edited form as:

*Am J Bioeth.* 2023 July ; 23(7): 103–105. doi:10.1080/15265161.2023.2214055.

## Unbounding ELSI: The Ongoing Work of Centering Equity and Justice

Chessa Adsit-Morris<sup>a</sup>, Rayheann NaDejda Collins<sup>b</sup>, Sara Goering<sup>c</sup>, James Karabin<sup>a</sup>, Sandra Soo-Jin Lee<sup>b</sup>, Jenny Reardon<sup>a</sup>

<sup>a</sup>University of California, Santa Cruz

<sup>b</sup>Columbia University

<sup>c</sup>University of Washington

ELSI efforts long have been troubled by critiques that they privilege scientific frameworks and grant scientists the power to set ethical agendas. As the first director of the Human Genome Project's (HGP) ELSI program, Eric Juengst, explained in reflections he wrote after leaving the role, the primary goal of the HGP's ELSI program was to support, not critique, genomics. "The enterprise of genome research and the knowledge generated by it," Juengst wrote, "were to be treated as 'unalloyed prima facie goods'" (Juengst 1996, 68). ELSI's aim was to create the policy tools that would ensure that these goods reached the public in the most efficacious manner. Rather than critically examining the role genomics played in reconstituting the natural and social order, the work of the ELSI program primarily focused on adapting existing ethical practices (e.g., informed consent) and legal instruments (e.g., patent law) to accommodate the new science. In short, to draw on and extend language that Melissa Creary (2021) powerfully provides, ELSI's formation was *bounded* by the narrow goal of facilitating genomics, a form of science it believed to be inherently good.

Thus, to date, ELSI has had little capacity to address issues of equity and justice. What then is its future in this moment when science policy organizations and funders are calling for equity-led approaches to science, technology, engineering, mathematics and medicine (STEM) research? The White House Office of Science and Technology Policy (OSTP) put forward at the end of last year an Equity Action Plan to transform the STEM ecosystem (OSTP 2022). The National Academy of Medicine's Committee on Emerging Science, Technology, and Innovation (CESTI) recently recommended that equity should be a core principle in governing emerging science and technology (Mathews, Balatbat and Dzau 2022). Both come in the wake of widespread calls to attend to the failure to recruit, support, and promote non-binary, gender non-conforming, disabled, Black, Indigenous, and other people of color (BIPOC) and women in STEM through developing policies, guidelines and frameworks to promote diversity, equity, and inclusion (see, for example, Atutornu et al. 2022; Fuentes-Afflick and Dzau 2022; Fletcher et al. 2022). All have put pressure on the

**CONTACT** Jenny Reardon, reardon1@ucsc.edu, University of California, Santa Cruz, Santa Cruz, CA 95064, USA.

**DISCLOSURE STATEMENT**

No potential conflict of interest was reported by the author(s).

ELSI community to expand its traditional scope and to do the transformative work needed to center the goal of creating just and equitable futures.

This work will not be easy, as it will require the fundamental and ongoing work of entwined intellectual and institutional change. Centering justice in science requires asking questions about the values and ideas that shape the institutions that fund and support scientific research. It entails turning a critical eye toward power relations and the (infra)structures that ground research institutions and their ethical frameworks (Reardon 2013). Thinking with Ferryman's engagement with Creary in this issue, it means paying attention to how we have "bounded" our conceptual frameworks in ways that too often limit what we mean by justice to mere inclusion at the table, a table that we have failed to notice is falling apart and may cause harm. As Ferryman (2023) warns, if we don't do the critical analytical and evaluative work required to unbound justice then our "well-intentioned inclusion efforts reproduce patterns of racialization" (31). Indeed, as Krystal Tsosie (2021) reminds us, *inclusion is not equity*—particularly if issues of justice are not central to the overall project of creating more ethical and equitable STEM practices. The critical question moving forward for ELSI practitioners is how can they pay attention to legacies of injustice, and their ongoing processes, rather than settling for "bounded justice" interventions?

The articles in this volume help with this by casting a critical eye on some of ELSI's most celebrated innovations and techniques—for example, community and public engagement efforts. Ever since the development of the International HapMap Project (HapMap) over two decades ago, community engagement has been a key ethical intervention used by genome scientists to reduce the chances of discrimination while also increasing the diversity of genomic data populations. Leaders of the HapMap—which was a worldwide effort to map human genetic variation—were keenly aware of the controversies sparked by the Human Genome Diversity Project (HGDP), an initiative that aimed to archive human genetic diversity by collecting the genomes of "isolated indigenous populations" (Reardon 2017). To distance themselves from the HGDP, HapMap leaders emphasized that they would sample "large populations" who held majority status in society and establish a robust community engagement program (NHGRI 2002). At the time, HapMap community engagements represented the largest investment of ELSI funds and deployment of ELSI researchers ever seen in genomics. However, they enacted an all too bounded approach to ethics that failed to understand the deeper questions of power and knowledge raised by both the HGDP and the HapMap: How should human groups be constituted and for what ends?

As Conley et al. (2023) in this volume note, while community engagement—as well as other public engagement efforts—have been nearly universally endorsed as a desirable and essential part of good governance, they often fail to engage these critical issues and questions. Through an analysis of five organizations' public engagement efforts, they find little evidence that public engagement advances equity, in part because of the ways in which both "public" and "engagement" become narrowly constructed and practiced. They observe that the publics engaged primarily consist of experts, and even when a more diverse public is engaged, they are still expert selected. Too often, they write, "the public will end up being those with the means, motive, and opportunity to hear about what is being done, and then come forward to express views" (Conley et al. 2023, 14). Thus,

public engagement frameworks can arguably perpetuate processes of marginalization and exclusion, in the name of inclusivity, if they are not attentive to past and ongoing injustices. Conley and coauthors conclude, and we agree, that there is often a separation between public engagement aspirations and how they are actually practiced.

The case of community engagement underscores the need for evaluating how commitments to ethics are implemented if they are to advance justice and equity. A justice-oriented approach, we argue, also needs to acknowledge and respect community practices of what Ruha Benjamin (2016) has named “informed refusal.” This requires attending to the ways in which historical injustice, exclusion, mistreatment, and marginalization are constant variables in ethical research interventions. We argue that there is an ongoing need not only to evaluate how commitments to ethics and equity—such as through community and public engagement—are implemented, but also to address deep seeded issues of mistrust that have resulted from bounded intellectual and institutional frameworks, including those produced by ELSI researchers.

Rebuilding trust and centering justice requires the ongoing transformative work of deconstructing existing intellectual and institutional systems. Drawing on a critical analysis of the power relations and (infra)structures that ground existing ethical frameworks is necessary to expand or “unbound” traditional conceptions of inclusion, diversity, and justice. This is a fundamental part of any effort to actively build up more equitable relations and practices. A foundation of trust can only be rebuilt and upheld when we move past simply acknowledging the historical legacies of injustice and begin to establish robust measures that take into account the nuances of marginalization, equity, and what it means to be genuinely inclusive (Lee et al. 2019). As we have stated elsewhere: “Ethical, just, and trustworthy science cannot be made from the margins” (Reardon et al. 2023). Unbounded conceptions of equity and justice must be central to this transformation.

## ACKNOWLEDGEMENTS

We would like to acknowledge the support and critical feedback from members of the Leadership in the Ethical and Equitable Design (LEED) of STEM initiative, which include the authors of this piece as well as Mildred K. Cho, Malia Fullerton, Evelyn Hammonds, and Aaron Panofsky. Many of the ideas in this piece emerged from our collaboration.

## FUNDING

This material is based upon work supported by the National Science Foundation under Grant No. SES 2220631.

## REFERENCES

- Atutornu J, Milne R, Costa A, Patch C, and Middleton A. 2022. Towards equitable and trustworthy genomics research. *EBioMedicine* 76 (103879):103879. doi:10.1016/j.ebiom.2022.103879. [PubMed: 35158310]
- Benjamin R 2016. Informed refusal: Toward a justice-based bioethics. *Science, Technology, & Human Values* 41 (6):967–90. doi:10.1177/0162243916656059.
- Conley JM, Cadigan RJ, Davis AM, Juengst ET, Kuczynski K, Major R, Stancil H, Villa-Palomino J, Waltz M, and Henderson GE. 2023. The promise and reality of public engagement in the governance of human genome editing research. *American Journal of Bioethics* 23 (7):9–16. doi:10.1080/15265161.2023.2207502.

- Creary MS 2021. Bounded justice and the limits of health equity. *The Journal of Law, Medicine & Ethics: A Journal of the American Society of Law, Medicine & Ethics* 49 (2):241–56. doi:10.1017/jme.2021.34.
- Ferryman K 2023. Bounded justice, inclusion, and the hyper/invisibility of race in precision medicine. *The American Journal of Bioethics* 23 (7):27–33. doi:10.1080/15265161.2023.2207515.
- Fletcher FE, Ray KS, Brown VA, and Smith PT. 2022. Addressing anti-black racism in bioethics: Responding to the call. *Hastings Center Report* 52 (S1):S3–S11. doi:10.1002/hast.1360. [PubMed: 35470874]
- Fuentes-Afflick E, and Dzau V. 2022. Inclusion, diversity, equity, and anti-racism in health and science professions: A call to action for membership and leadership organizations. *NAM Perspectives. Commentary, National Academy of Medicine, Washington, DC.* doi:10.31478/202205b.
- Juengst E 1996. Self-critical federal science? The ethics experiment within the U.S. Human Genome Project. *Social Philosophy & Policy* 13 (2):63–95. doi:10.1017/S0265052500003460. [PubMed: 11653300]
- Lee SSJ, Fullerton SM, Saperstein A, and Shim JK. 2019. Ethics of inclusion: Cultivate trust in precision medicine. *Science (New York, N.Y.)* 364 (6444):941–2. doi:10.1126/science.aaw8299. [PubMed: 31171685]
- Mathews DJH, Balatbat CA, and Dzau VJ. 2022. Governance of emerging technologies in health and medicine—Creating a new framework. *The New England Journal of Medicine* 386 (23):2239–42. doi:10.1056/NEJMms2200907. [PubMed: 35417635]
- National Human Genome Research Institute. 2002. International consortium launches genetic variation mapping project. Last modified April 29, 2010. <https://www.genome.gov/10005336/2002-release-genetic-variation-mapping-launch>
- Office of Science and Technology Policy. 2022. Office of science and technology policy executive order 13985: Equity action plan. [https://www.whitehouse.gov/wp-content/uploads/2022/04/04-2022-EO13985\\_OSTP\\_EquityAction-Plan\\_FINAL.pdf](https://www.whitehouse.gov/wp-content/uploads/2022/04/04-2022-EO13985_OSTP_EquityAction-Plan_FINAL.pdf)
- Reardon J 2013. On the emergence of science and justice. *Science, Technology and Human Values* 38 (2):176–200. doi:10.1177/0162243912473161.
- Reardon J 2017. *The postgenomic condition: Ethics, justice, knowledge after the genome.* Chicago, IL: University of Chicago Press.
- Reardon J, Lee SSJ, Goering S, Fullerton MS, Cho MK, Panofsky A, and Hammonds EM. 2023. Trustworthiness matters: Building equitable and ethical science. *Cell* 186 (5):894–8. doi:10.1016/j.cell.2023.01.008. [PubMed: 36724788]
- Tsotie K 2021. Inclusion without equity: The need to empower indigenous genomic data sovereignty in precision health. In *Remapping race in a global context*, ed. Lorusso L and Winther RG. London: Routledge.