

# Thesis: The Human Genome Project and ELSI: The Imperative of Technology and Reduction of the Public Ethics Debate

Editor's note:

Tito Brige Carvalho defended his thesis titled "The Human Genome Project and ELSI: The Imperative of Technology and Reduction of the Public Ethics Debate" in April 2012 in front of committee members Jason Robert, James Hurlbut, and Karin Ellison, earning him a Master of Science degree. <https://repository.asu.edu/items/14974>

Abstract:

In the past century, a number of technological projects have been undertaken as grand solutions to social problems. In the so-called century of biology, this technological world view focuses on biomedical advances. Portrayed as the Manhattan Project of the late 20th century, the Human Genome Project, or HGP, not only undertook the science of sequencing the human genome but also the ethics of it. For this thesis I ask how the HGP did this; what was the range of possibilities of goods and evils imagined by the HGP; and what, if anything, was left out. I show that the Ethical, Legal, and Social Implications, or ELSI, research program of the HGP was inscribed with the competencies of the professional field of bioethics, which had lent itself useful for governing biomedical science and technology earlier in the 20th century. Drawing on a sociological framework for understanding the development of professional bioethics, I describe the development of ELSI, and I note how the given-in-advance boundaries between authorized and unauthorized questions shaped not only its formation but also biased technologically based conceptualizations of social problems and potential solutions.

In this sense, the HGP and ELSI served both as the ends of policy and as instruments of self-legitimation, thus reinscribing and enacting the structures for those powerful sociotechnical imaginaries. I engage the HGP and ELSI through historical, sociological, and political philosophical analysis, by examining their immediate context of the NIH, the meso level of professional and disciplinary bioethics, and the larger context of American democracy and modernity. My argument is simultaneously a claim about how questions are asked and how knowledge and expertise are made, exposing the relationship between the HGP and ELSI as a mutually constitutive and reciprocally related form of coproduction of knowledge and social structures. I finish by arguing that ELSI is in a better position than bioethics to carry out the original project of that field, i.e., to provide a space to elucidate certain institutionally authorized questions about science and technology. Finally, I venture into making a prophecy about the future of ELSI and bioethics, which is that the former will replace the latter as a locus for only formally rational and thin ethical debates.