

Week Nine Reading Guide: Concerns about genetic engineering

This week, three students will present 15-minute summaries of their final paper concepts. We will also have Jonathan Beckwith as a guest speaker. Readings for the first class are from Beckwith's book, where he shares several examples of social and ethical implications of research in the life sciences, including the misuse of science to subjugate different groups of people. The last chapter we read this week describes Beckwith's efforts to work within the existing power structure of biology research to shift it to greater social responsibility. Such change often occurs so slowly that it only becomes apparent after several decades. We will compare the original report of the ELSI Working Group's plans with a later article seeking to apply the lessons learned to nanotechnology research. The implications for present-day MIT should be apparent.

November 6, 2019

Beckwith, J. 2002, Chapters 8–12.

Chapter 8

- Beckwith describes the hazards of scientists not speaking out on the social implications of science, and not correcting errors. How does this relate to the status of XYY people?
- When Beckwith found evidence of misconduct by the chair of the Harvard Medical School Institutional Review Board regarding an XYY study, he and an MIT professor went public and then tried to organize faculty support for a resolution calling for the case to be examined. Why did he lose the vote and what were the consequences? How is this case relevant to current discussions about ethics at MIT?

Chapter 9

- How did Beckwith respond to E. O. Wilson's claims about sociobiology in 1975?
- How was Wilson's work used to attack feminism and promote racism?
- What do you think would happen today if a group of students poured water on a controversial speaker?
- Why was the Sociobiology Study Group long-lasting and effective?

Chapter 10

- How and why did the culture of science change through the 1960s and 1970s? During that time, were there consequences for challenging "the myth that science is a neutral pursuit, uncontaminated by social and political concerns"? How had things changed by 1990, and why?
- If 3 to 5% of the cost of the Schwarzman College of Computing were set aside to study the Ethical, Legal, and Social Implications of AI, how much money would that be? Compare it with MIT's investment in two other big projects: The Engine and MITx/edX.

Chapter 11

- How do scientists maintain the status quo in their disciplines? How do innovators change the culture and practice of science?
- Does the failure to value narrative (storytelling) detract from the practice of science? How does it affect the understanding and use of science by the public?

- On ethics (pp. 188–190): Is Beckwith a consequentialist or a deontologist? Do you think his political motivations driven by an ethical theory (if so, which one), or something else?

Chapter 12

- Do you think Beckwith was naïve to join ELSI and thereby work within the system sponsoring the Human Genome Project? Was there a conflict of interest? What principles guided his choices?
- Why did some powerful biologists oppose the ELSI Working Group?
- How might ELSI have been influenced by Beckwith’s experience with the Sociobiology and Genetics Screening Study Groups?
- What happened to ELSI when the NIH Director changed, and why?
- What obstacles existed to collaboration between science and the humanities in the 1990s? Are they the same now?

November 13, 2019

National Human Genome Research Institute 1996, *Review of the Ethical, Legal and Social Implications Research Program and Related Activities (1990-1995)*.

Available online at: <https://www.genome.gov/10001747/elsi-program-review-19901995>.

What charge did the National Center for Human Genome Research provide to the ELSI Working Group? What goals did the Working Group set? Were those goals met?

What governmental organizations did the ELSI working group collaborate with after its formation in 1989?

How well did the nine original issues identified in the ELSI program announcement of 1990 match the topics listed in Table 1? What issues appear to have been dropped?

How many research projects did the ELSI program fund in each of the four program areas during 1990–95? Describe one research project that stands out to you.

One of the stated goals was to “develop policy options that would ensure that [genetic] information is used for the benefit of individuals and society.” According to this report, why did that prove difficult?

What legislation was introduced in 1995–96 to address the issue of genetic discrimination in health insurance? When was the Genetic Information Nondiscrimination Act passed and what uses of genetic information did it make illegal?

Fisher, E. 2005, “Lessons learned from the ethical, legal and social implications program (elsi): planning societal implications research for the national nanotechnology program,” *Technol. Soc.* 27, 321–328.

<http://doi.org/10.1016/j.techsoc.2005.04.006>.

In what ways, according to this article, did the ELSI program fall short in influencing policy around applications of genetic research? What did a 1996 review recommend to solve these problems? These recommendations were not fully implemented. Why not? Does this article suggest that ELSI's stated attention to policy influence was merely a public relations shield?

How does the 21st Century Nanotechnology Research and Development Act attempt to build meaningful policy development into nanotechnology research efforts?

Has there been a similar ethical research program funded nationally for artificial intelligence research? Why or why not? What is different about this field compared with the genetics revolution launched by the human genome project?

What is the Collingridge dilemma?

What role did Beckwith play as a science activist in ELSI? What activist methods did he use? Would those methods be effective in the artificial intelligence revolution currently underway? Why or why not?

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