

Jenny Reardon

The Postgenomic Condition: Ethics, Justice, and Knowledge after the Genome

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Quote: "In her study of genomic science and technology, Reardon poses the political questions: what should we 'gather around and constitute as public goods? What is the place of genomics, biotechnology, and biomedicine in constituting these goods? How do we decide? Who are "we"?"

The double helix structure of a DNA molecule--with its two strands of nucleotides twisting around each other--has become an icon of not only contemporary science, but perhaps also science policy. The Human Genome Project included the US government's first and most major investment in normative and conceptual research, the Ethical, Legal and Social Implications (ELSI) Research Program. Mapping the genome has captured the public's imagination--and the latest biological Big Science project of precision medicine calls for public participation--in a way that no other Big Science initiatives have.

Four different nucleotides--each composed of a sugar, a phosphate group, and one of four nitrogenous bases: adenine (A) usually paired with thymine (T), and cytosine (C) with guanine (G)--are the building blocks of DNA with hydrogen bonds between them connecting the two strands. Single nucleotide polymorphisms (SNPs)--substitutions of one nucleotide for another that constitute the most common form of genetic variation between people--are used as markers to help to identify genes, the functional units of heredity, related to conditions of interest (traits, diseases). This genetic account of human variation is complex, but well-organized.

The same may be said for Jenny Reardon's complex but clearly structured account illuminating the intertwined strands of political commitments and scientific assumptions and goals underlying recent decades of genetic research. Value, meaning, information/knowledge, and sameness/difference serve as the interconnected building blocks of her analysis. Core concepts of liberal democracy--information, inclusion, people/persons, property, privacy, and public--serve as the markers of the conditions of interest to her: "conditions for life, thought, and politics" that may be supported or undermined by science and technology.

One may quibble, as Rosario Isasi does, that in her focus on postgenomic political life, Reardon undervalues the benefits of advances in genomic science for understanding, diagnosing, preventing, and treating health conditions that dramatically affect individuals' lives (Isasi 2017). Reardon also does not explore the typical ELSI issues associated with newborn screening, prenatal testing, predictive genetic risk analysis, and pharmacogenomics. Her project is a different one, exploring structural ethics (Brey 2014) rather than focusing on ethical questions faced by individual moral agents or even groups of decisionmakers formulating policy. The result is a book that is equally valuable as a work of science and technology studies and as a work of applied political philosophy.

Reardon's book is a skillful mixing of narrative methods and philosophical argument. She presents her argument by analyzing five constellations of research projects. Drawing on her interviews with key players, as well as popular, scholarly, and scientific literatures and her own experiences as both biologist and patient, she constructs five engrossing narratives that illuminate how "liberal dreams of good government grounded in freely accessible information" became "harnessed to genomics" and how "genomic 'information' produce[s] the postgenomic problem of meaning" (24). Together these narratives provide an insightful map of the genomic terrain in the US (but with consideration of international efforts and the impact of globalization) from the 1990 launch of the Human Genome Project to the preconditions and conceptual context of the current All of Us Precision Medicine Research Project.

Reardon employs Enlightenment conceptualizations of reason and value--coupled with classical liberal (for example, Adam Smith's) conceptions of the relationship of equality, rights, and economics--as the conceptual equivalent of a reference genome. She then traces how genomic research, informatics, globalization, and capitalism have not only disrupted this equality-rights-economics relationship, but have also shaped genomic science.

Reardon argues that, as algorithms have replaced hypotheses in genomic research, our view of genomes themselves has shifted: from genomes with economic and epistemological value to be discovered, to genomes to which meaning and value must be attributed. One might think that given the field's most recent preoccupation with genomic sequencing and "data mining," genomes would now be viewed as sources to be mined to discover meaning and value. But this would be to focus on the creation and mining of raw genomic data, and to ignore the need for it to be interpreted if it is to have meaning and then value. It would be, as Reardon points out, to focus only on the part of genomic sequencing that has indeed followed Moore's Law (describing the falling cost of increasing computer power) to give us the <\$1000 genome, while ignoring the costs of data interpretation that have not followed suit.

Moreover, Reardon points out that the interpretation of data produced by sequencing machines is performed by people and companies with "a discerning eye, not the 'God's eye' of aperspectival objectivity" (139). Indeed, Reardon shows that rather than debating which genomic *data* to use and trust, or what *criteria* to use in evaluating studies, public and political debate about how to interpret genomic data has focused on *whom* to trust to generate and interpret data--US government-funded or corporate-employed researchers, citizen scientists, or genomic research initiatives abroad. Reardon's discussion of non-US initiatives is instructive, because she notes how they are subject to different conflicting interests and constraints--both fiscal and in terms of

the richness of their populations' genetic diversity--from those of the US. Reardon also traces the shifting value of genetic diversity: relatively small, isolated, homogeneous populations were the ideal context for early genetic studies, whereas current genomic research requires large study populations that are, ideally, representative of the diversity of the broader population in which findings will be applied.

Titles of the chapters analyzing the five narratives through which Reardon traces recent genomic research emphasize the political philosophical themes she finds the projects' narratives to reveal. She demonstrates how different liberal concepts were critical at different stages of the genomic research enterprise: information giving way to an emphasis on inclusion, then to a focus on persons (22). She analyzes the origins of the Human Genome Project and early projects examining human diversity or genetic variation in the US and internationally; then she turns to projects like Iceland's deCODE, the UK Biobank, and Generation Scotland, which presented nation-states with the opportunity to "create new natural resources out of the bodily tissues of their citizens at a time when resources in their lands and seas were disappearing" (94). Reardon next examines direct-to-consumer personal genomics companies against the backdrop of growing skepticism about the credibility of social institutions, a social climate preceding and eventually producing our current post-truth politics. The first decade of the twenty-first century witnessed tussles between the public and private sectors for control of data and development of sequencing and informatic technologies necessary to make meaning and value out of individuals' genomes. Reardon describes a lawsuit brought against 23andMe that alleged the "test results were meaningless" and had value only for the company that could transform them into "databases and statistical information" that could be marketed to others (122 and fn. 8). Questions of openness/privacy and property shape Reardon's analysis of the next narrative of the Personal Genome Project. Throughout, Reardon describes how "grand narratives about the link between science and a more just world became central" (19) to the marketing of each of the projects. She also analyzes not only the actual impact on social justice of the unfolding of these projects, but also the impact on liberal democracy of the particular conditions--material, social, and conceptual--that were necessary for the projects to unfold as they did.

By the time President Obama was in the White House advocating not only for health care as a right, but also for development of the Electronic Health Record and the amassing of vast amounts of data about patients' health conditions (and the quality of health care) that would make health care affordable and portable, the material conditions--informatic and genomic technologies--were in place to begin to make that political vision a reality. In the process, Reardon observes that the Precision Medicine Initiative, rebranded the All of Us Research Program, exemplified how "support for public dialogue has transformed into support for public relations" (179). She concludes that "instead of understanding what people want and believe and then attempting to create practices and policies that align with the will of the people, today's precision medicine initiatives begin with the policy--share data--and then attempt to 'put' ideas into citizens' heads that will make them want to comply" (180). She notes that "there is little space for critical discussion . . . little if any space to ask who benefits. . . . [T]he answer is given: we all will if we give our DNA and data. This . . . is how a new social contract with biomedicine forms" (180). Yet Reardon urges that we must examine and address how this transformed social contract and its "biological and informatic infrastructures . . . differentially affect citizens" (181). She goes on to offer "a few modest proposals." But it seems that more ambitious lessons for the

present are contained in Reardon's analyses of early research initiatives, particularly those that reflected antiracist ambitions of late-twentieth-century genetics.

Consider Reardon's narrative analysis of research involving Tuskegee University (TU)--not the infamous "Tuskegee Study of Untreated Syphilis in the Negro Male," but attempts to establish a genome sequencing center at Tuskegee. Reardon recounts that geneticist and Tuskegee faculty member Ed Smith "believed that if the Human Genome Project was to be the next Apollo project, a 'holy grail' of both great economic and symbolic importance, then African Americans should take part" (57). Reardon analyzes challenges faced by projects seeking to recruit participants in the "Black Belt" in order to characterize African Americans at the genomic level. One project, "Linkage Disequilibrium Analysis of the DARC Gene Containing Region . . . of Chromosome 1," sought to examine a variant of the Duffy Antigen/Chemokine Receptor Gene Containing Region thought to be protective against malaria and to be present in 100% of African Americans and 0% of whites, which was thus posited to provide a way of measuring admixture of African and non-African genomes (59-60). A study of genetic risk for heart disease in African Americans was proposed to bring funds for genomic sequencing and research training to TU in a manner that disturbingly echoes the early welcoming of the Tuskegee Syphilis Study for the sake of resources that it would bring from the Public Health Services to the impoverished rural South.

Reardon's analysis of these projects provides specific lessons for contemporary genomic investigators and science policy. One lesson is found in the worry of those close to the TU study that "so many expressed interest in taking part not because they wanted to participate in scientific research but because 'we have twenty-five bucks attached to it'" (60). Interestingly, contemporary ads recruiting All of Us research participants similarly offer them \$25.

Another lesson instructive for today's All of Us Research Program lies in Reardon's account of the disappointment experienced by people who *did* want to contribute to science and who "after years of being told about the great value of genomic data . . . have taken part in genomics" and have learned that either their DNA was not used . . . [or] is stored in a biobank where proper administration has become the overriding concern" (178). This presages the likely fate of many of the contributions made to All of Us, which will not be analyzed to address specific research questions and thus will not yield and return to individual contributors information that will help them improve their health, as current advertising promises (Sankar and Parker 2017).

The most important message from Reardon's interviews regarding these early projects is also an insight most persistently ignored today. As one of her interviewees said "bluntly: 'Let me say this, and I think this is real important, and it's the truth as I see it: it [genetics] is not important. And it is not important because there is *so much else wrong*'" (64). Unlike most ELSI research that focuses on how genetic research should be ethically conducted, Reardon's analysis invites us to take seriously the question of *whether* it should be pursued for the reasons and on the scale that it currently is and inevitably will be.

Despite this inevitability, we can attempt to create the conditions for life, thought, politics, and justice--and for genomic research that, in turn, supports these aims. The attempt involves an explicit return to the goals that grounded the initiatives Reardon examines: countering racism, democratizing science, providing means to understand and improve human health. It involves

explicitly rejecting the turn that Reardon demonstrates each initiative eventually took: to create something--anything--of value from genomic data, rather than using the data to explain or answer something of value. We will need to develop machines and algorithms to yield information answering research questions of value to people, not the reverse: obtaining information that answers the needs of the technologies whose value derives from markets separate from and perhaps opposed to the ethical values and political interests of the people providing the information. Moreover, as researchers recognize, for genomics to be valuable, what is really needed is data and DNA from all of us--or at least from a sample representative of all of us--and therefore, the research questions posed and the knowledge to be obtained would really need to be of value to us all.

In her study of genomic science and technology, Reardon poses the political questions: what should we "gather around and constitute as public goods? What is the place of genomics, biotechnology, and biomedicine in constituting these goods? How do we decide? Who are 'we'?" These "fundamental questions about how we should know and live in the world in the midst of the rise of informatic capitalism, growing inequalities, and intensified processes of biomedicalization lay barely beneath the surface" of the genomic initiatives she so incisively examines. Addressing these questions, she argues, will require long-term investment not in Big Science but in "institutions that support the *arts of collective judgment*" (184). Reading her book is a worthwhile investment in developing an understanding necessary to make a valuable contribution to that collective enterprise.

Reardon's book is particularly valuable for those interested in the relevance of feminist theory for rhetoric and philosophy of science, political philosophy, or analysis of sea changes in social thought and public perception. In addition to grounding her analysis in the experiences and vantage points of both scientists and those affected by their projects, Reardon makes use of key insights from Pierre Bourdieu, Bruno Latour, Jean-François Lyotard, and especially Hannah Arendt. She illuminates the normative assumptions and exercises of power, as well as the contingent technological developments, that structured particular projects' hypotheses and later led to the abandonment of hypothesis-driven genomic science. Reardon examines genetics as a specific instance of the general influence of science and technology on politics and differently situated publics. The result, an account of the intertwining intellectual and material conditions informing twentieth-twenty-first-century genomics, may justifiably be considered a profound analysis of both science and our postgenomic sociopolitical condition.

References

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