

THE MORAL HEART OF GENOMICS AND THE
FAILURES OF LIBERALISM

Jenny REARDON, *The Postgenomic Condition. Ethics, Justice &
Knowledge after the Genome*
(Chicago/London, The University of Chicago Press, 2017)

Professor of Sociology at UC Santa Cruz and Director of the Science and Justice Research Center, Jenny Reardon proposes in this book an exciting series of stories illuminating the complex sociopolitical issues embedded in the production and interpretation of genomic data. Reardon's main contention is twofold: (1) in contrast with the 1990s and its dominant technocratic approach, the genomics of the 2000s has been fueled by liberal and democratic values, "genomic liberalism"; (2) despite the scientists' good intentions and the public's high expectations, this liberal moral economy repeatedly failed to address the fundamental questions of justice raised by contemporary genomics. Hence, the critical diagnosis running throughout the book of a quasi-structural inability of "postgenomic" projects, devices and procedures to provide solid "grounds [for] public trust or ethical action" [181].

The stories gathered here are chronologically ordered and, as different liberal concepts were salient at different times, each chapter focuses on a different core concept of liberal democracy: information, inclusion, participatory governance, etc. Chapter 2—*The information of life or the life of information?* [25-45]—sets up the general historical background. It recalls that in the mid 1990s it was one of the proclaimed objectives of the Human Genome Project (HGP) to establish the free flow of information "at the moral heart of genomics" [29]. And as a matter of fact, HGP leaders agreed in 1996 on common principles requiring that all genomic information be released in publicly accessible databases. However, not only did this ideal of "openness" create unexpected inequalities between scientists, it launched a technological race propelled by unprecedented flows of capital into the life sciences, private and public. Reardon's main claim here is that from this perspective it makes no sense to contrast the alleged "disinterestedness" of HGP leaders and the explicit commercial interest of early entrepreneurial scientists (such as the famous former NIH researcher, Craig Venter): they all contributed, in one

way or another, to transform biology “into an industrial-scale production system” [37] and to the final “takeover of genomics by the logics and practices of informatic capitalism” [38].

This industrialization of life sciences based on the ability of sequencing machines to transform DNA into digital information has given life to a deluge of digital data. And genomics is frequently depicted as a purely data driven science.¹ Yet, to understand our “postgenomic condition” one needs more than just to celebrate the techno-scientific achievements responsible for this deluge. One needs to scrutinize the difficulties and uncertainties generated by the successive attempts to make sense of this ever-increasing amount of shared data. Each chapter of the book focuses on one of these attempts: The Human Genome Diversity Project [chapter 3: 46-69], The HapMap project [Chapter 4: 70-93], Generation Scotland [Chapter 5: 94-119], 23andMe [Chapter 6: 120-144], The Personal Genome Project [Chapter 7: 145-168]. But, ultimately, each chapter tells the same story over and over: genome scientists relying on liberal values to forge socially valuable knowledge but remaining deeply unable to provide definitive or at least convincing answers to some of the critical questions raised by Reardon throughout her book: “What is the value and meaning of an endeavor that requires an ever-growing number of automated sequencers to displace humans and that consumes large amounts of reagents and capital?” [27]; “Who are the people who should have the right to be included and represented in maps of the human genome? What should that right of representation entail?” [92]; “Can any person—including biological and medical experts—interpret genomic data in a manner that produces valuable knowledge for scientific and social life?” [122]; “Might the embrace of openness unwittingly install scale and efficiency as the driving imperatives of genomics, displacing the broader goal of building a genomics that is of, for, and by the people?” [168], etc.

The Postgenomic Condition is more than just an admission of ignorance and a list of unanswered interrogations. Reardon’s book brings at least three significant transversal contributions. First, this book is an interesting addition to the previously available studies on the nature and consequences of “genomic regime”.² Reardon’s

¹ As one of the scientists interviewed by Reardon states: “generally our philosophy is to gather a lot of data and try and let the data speak for itself, and find out what stories there are inside” [142].

² See for instance A. Bonaccorsi, 2008, “Search regimes and the industrial dynamics of science”, *Minerva*, vol. 46; S. Hilgartner, 2017, *Reordering Life: Knowledge and Control in the Genomics Revolution*, Cambridge Mass., MIT Press.

journey through these different projects—HGDP, HapMap, GS, PGP, etc. provides readers with the opportunity to realize that, from its nascent stages in the 1990s to its most contemporary advances, technological innovation has always been an integral part of the genomic regime: “the meeting of the private property regimes of technological innovation with the Mertonian norm of scientific openness created a formative tension that powerfully shaped genomics from its start” [31]. But genomics is not just a “property regime” born from the combination of public and private, scientific and technological interests. It is also a specific “regime of truth” and “knowledge-objects” where computers and digital data infrastructure play a central role. In most of the projects analyzed in the book, the views and beliefs of scientists as well as those of the public receive recognition insofar as they meet the computer and data scientist requirements of normalization and standardization. Bioinformatics is not just a tool here; it becomes an epistemic frame and, for some, an end in itself with high degrees of technological and capital concentration: in 2015 one company—Illumina Inc.—produced 90% of all the DNA data available.

A second strong contribution of Reardon’s work is the connection it makes between this technological inclination and rich normative and ethical interrogations: “How within genomics did efforts to democratize and to create justice become harnessed to the rise of the machines?” [19]. This is precisely one of the core interrogations of the book. Reardon makes it clear from the start: her investigation is built on interviews and meetings with genome scientists, social scientists, informaticians, genetic counselors, bioethicists, social activists, lawyers, entrepreneurs, and policy makers “who shared a desire to ensure that human genomics made good on its original promise: that it would represent all humans; that it would help build a better future for everyone” [23]. Although the reader may find this picture of the genomic stakeholders way too idealistic, it is undeniable that genome scientists, far from being neutral or “value free”, have continuously expressed and/or endorsed a wide range of normative and political considerations. It is striking to notice how initiatives such as 23andMe and the Personal Genome Project, despite all their differences, converge to criticize the state and its regulatory representatives. The leaders of the “personal genomics revolution” consider themselves as the vanguard of a scientific but also a political revolution against a “mindless technical bureaucracy”, “a genomic technocracy” that grew up mainly at NIH during

the decade of the Human Genome Project. In the name of “openness” and the “free flow” of information, their proclaimed aim is to weaken as much as possible what they perceive as an “unjust state regulation” [144]. In this matter, *23andMe* [chapter 6] is a fascinating sociological case study. Not only did the company try to challenge the “bioethical constructions of who could be a subject of human genetics research” [133], but it also promoted a profile of corporate researcher blurring the traditional normative demarcation between academia and industry.

Finally, the third contribution of the book will be of greater interest to social scientists themselves. Throughout the successive chapters, Reardon shows how, since the 1990s, social scientists have had many opportunities to collaborate with genome scientists—with contrasted results. Many of the projects discussed in the book deal with the sensitive issue of genomic diversity. Most of them were based on the idea that it would be easily possible to identify a variety of “communities” to be sampled and investigated, and most of them have tried to promote “community engagement” instead of “community consultation”. However, notes Reardon, while they offered theoretically “new power to ‘communities’, it proved far from self-evident who these ‘communities’ were who could take up these new rights” [79]. It has frequently been one of the social scientist’s important tasks to “construct” these biosocial communities with a certain degree of precision and representation. The case of Generation Scotland (GS) discussed in chapter 5 is remarkable. Reardon recalls that sociologists of science and medicine took part in GS from the very start of the initiative and held seats in its scientific committee. They have been considered as experts on the “views and preferences of the Scottish people”, and they employed mixed-method research (focus groups, in-depth interviews, public surveys, exit questionnaires, and ethnography) to inform their colleagues about the “preferences” and “will” of the population regarding their own research design. One of the strong outcomes was that most of the population studied was willing to participate in the study if the benefits of the study would be at least partly shared with the public. As emphasized by Reardon, although this principle of “public benefit sharing” has been one of the clearest outcomes of the sociology involved in GS, it has also been a particularly difficult outcome to secure in the long run: “Benefit sharing proved a test case. Yet, as a case, it proved inconclusive. [...] during my second GS

fieldwork trip, concerns arose about whether GS would support benefit sharing” [105].

Just like Generation Scotland, most of the projects considered in this book have failed to create the conditions needed for a more democratic and just society. And there is obviously something disconcerting about genomics scientists striving to diversify the populations studied while most of the same populations are still deprived basic health care. Although this lesson drawn from *The Postgenomic Condition* needs to be heard by social scientists and policy makers, one should be careful not to draw rapid generalizations or misinterpretations. Reardon repeatedly claims that she wants to depart from the “popular accounts” of genomics and their binary frame: public vs private, inclusion vs exclusion, etc. However, not only is much of her own analysis based on a too simplistic opposition between humans and non-humans— “[...] genomics ushered in a technocratic and capitalist mode of producing information, one in which computer-run machines designed to increase speed and efficiency replaced humans who sought knowledge and justice” [27]—but she seems occasionally to entangle two different questions: “is genomics a good science?” and “is genomics a science at all”? Although consistent with her “coproduction” theoretical framework,³ this confusion is questionable as it tends to merge two different levels of analysis—normative and cognitive—and at the end to strengthen a skeptical representation of the genomic regime. It is one thing to say that a project’s failure stems from its inability to produce ethical and political tools that could work in an efficient manner with scientific and technical ones. It is quite another to claim that this failure results from the scientific and technical tools themselves and their inability to produce real findings, positive or negative. “I play throughout [the book]”, writes Reardon, “with the suggestion that it may be more illuminating to think of this time after the human genome [...] as an age ‘in-formation’ where little is known, and much is promised” [174]. But is this true? Is our postgenomic condition a pure admission of inhumanity and ignorance? Has genomics systematically failed to create “much of medical value” [176]? As the researchers themselves have still not reached consensus on this issue, one should be careful before providing any definitive answer to this question. For ten years now, studies have compared millions of DNA sequences that vary from one individual to the other, revealing progressively the variants

³ See also J. Reardon, 2001, “The Human Coproduction,” *Social Studies of Science*, 31/3: 357-388.

associated with various pathologies. The “rise of the machines” condemned by Reardon has had an obvious impact on scientific research: the genome-wide association studies mentioned here for instance would not be possible without such machines. But this research-technology regime⁴ does not replace preexisting research practices. In most contemporary translational settings such as the NIH Undiagnosed Diseases Network (UDN),⁵ the latest progress of knowledge depends on the ability of clinical researchers to combine and interpret all types of data, genotype and phenotype. In all cases, before producing any comprehensive assessment of advances and failures in genomics, the sociologist of science should carefully and empirically analyze the nature and extent of the controversies associated with their measurement. Finally, if the vision of the scientific (un)achievements of contemporary genomics provided by Reardon’s book deserves to be nuanced, her recommendations [chapter 8] need some further elaboration (perhaps in a future book?). In a brief paragraph, she recalls for instance that when the Human Genome Project was first launched, there existed in the United States an Office of Technology Assessment (OTA), which was closed in 1995. She claims that, in order to solve the problem of public engagements in science and technology, “it is time to revisit the need for an institution that can support critical public deliberation of science and technology” [197]. Sure, why not? But also why not now look beyond US frontiers? It is interesting to note that the former OTA has been a role model for many existing offices of technology assessment around the world. In Europe, for instance, these offices have been partly coordinated by the European Parliamentary Technology Assessment (EPTA) network. However, the few available studies devoted to these offices show that their very existence is far from guaranteeing public engagement and any form of informed democratic representation.⁶ Although necessary, institutional spaces are simply not sufficient, and what is needed here is an in-depth analysis of the scientific and social conditions of public engagement on controversial issues. In France, for example, only one experiment on genetically modified organisms has received official support from the

⁴ B. Joerges and T. Shinn, eds, 2001, *Instrumentation. Between Science, State and Industry* (Dordrecht/London/Boston, Kluwer Academic Publishers).

⁵ R.B. Ramoni *et al.*, 2017, “The Undiagnosed Diseases Network: Accelerating Discovery about Health and Disease”, *The*

American Journal of Human Genetics, 100 (2): 185-192.

⁶ See M. Dubois, E. Schultz, eds, 2019, “Special issue on the Office parlementaire d’évaluation des choix scientifiques et technologiques”, *Histoire de la recherche contemporaine*, 1.

country's OTA (the OPECST) in 1998.⁷ There is no doubt that social scientists should further study these institutional spaces and their necessary conditions in order to improve the dialogue between science, technology and society.

MICHEL DUBOIS

⁷ D. Boy, Kamel D. Donnet and P. Roqueplo, 2000, "Un exemple de démocratie participative: la 'conférence de citoyens' sur les organismes génétiquement modifiés", *Revue française de science politique*, 50, 4-5: 779-810.