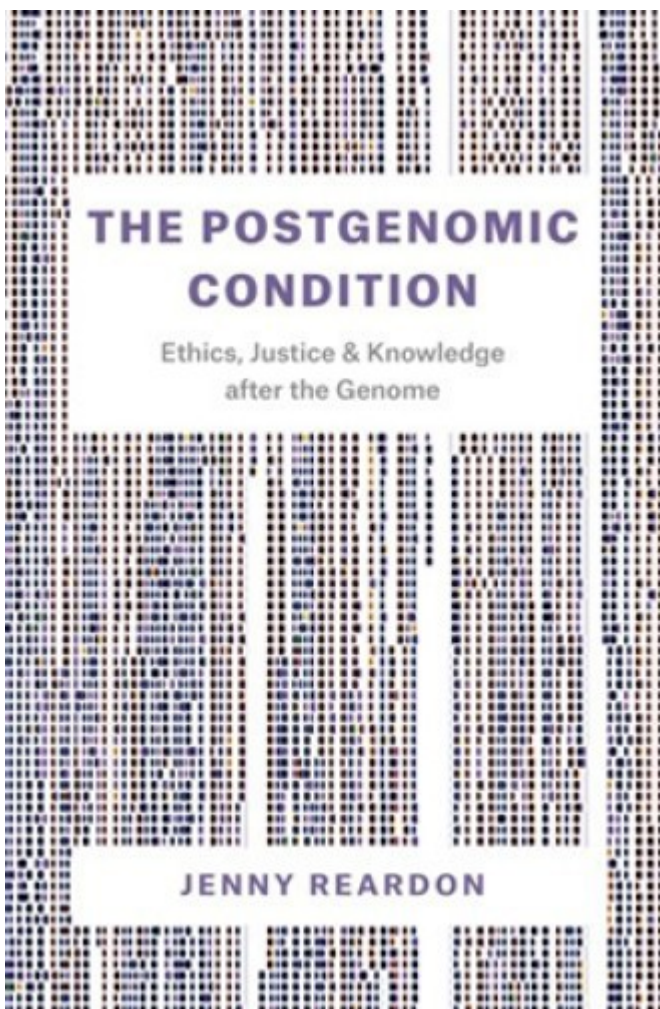


Who is genetic analysis for?

## **There are ethical reasons to think twice before sending off your DNA.**

by [Justin List](#) in the [November 7, 2018](#) issue

### **In Review**



### **The Postgenomic Condition**

Ethics, Justice and Knowledge after the Genome

By Jenny Reardon

University of Chicago Press

I remember wondering about how secure my DNA would be before I spat into a tube to be sent off for genetic analysis. Despite the risks, I thought I might learn something interesting about my family's migration over thousands of years and contribute to some greater knowledge that researchers are piecing together about the human story. At the time, I knew of no one close to me who felt comfortable sending off his or her genetic material. Sociologist Jenny Reardon identifies me as the perfect audience for the marketing of the test. Those willing to pay for DNA analysis, she says, belong to "a certain demographic that is more likely to be educated," "who understood genomics," and are likely to self-identify as white men.

Reardon is founding director of the Science and Justice Research Center at the University of California–Santa Cruz. She found herself interested in molecular genetics before pivoting into the emerging field of science and technology studies in the late 1990s. Her father, a former Jesuit priest influenced by Pierre Teilhard de Chardin, taught her early in life about the evolving potential of humanity and genetics. While traces of de Chardin's influence appear throughout the book, she more often draws on the work of political theorist Hannah Arendt and philosopher Jean-François Lyotard, especially in coining the phrase "postgenomic condition." She defines this term more by a set of questions than declarative statements. The postgenomic condition is that of attempting to understand the value of the human genome and genetic data collected in an era marked by distrust in institutions and rife with health and economic disparities.

She organizes her inquiry mainly around efforts to collect and decode genomic material from various populations around the world, such as Alabama, Scotland, and Nigeria. These projects raise questions about the privacy of the genetic information collected and about what constitutes ethnic or national identity.

Reardon sharply questions the notion that the benefits of genomics will end racist science, bring forth distributive justice in science and health, overcome and in some cases redefine privacy issues, and be accessible to all. In all these areas, the effect of the postgenomic condition is much more uncertain. The Generation Scotland genomic databank, for example, was pitched to Scottish citizens as a national resource that would remain confined to Scotland's people and scientists. A dizzying array of novel privacy issues arose when foreign researchers equipped with different

technology sought to use the data. The Scottish citizens and government had to reexamine the project's social contract.

Other questions weave throughout these stories. Can we understand a decoded genome? Not now, for the most part. Can institutions promise data privacy in both the short term and the future? Doubtful. Who counts as a member of a biopolitical group when collecting and conducting genetic analysis? Unclear.

Reardon's concerns about companies and institutions overpromising what decoded information might mean, combined with the public's limited ability to understand genomics and how it might be used, remind me of how early scientists are in their efforts to use such data. One challenge is that even when scientists locate a particular gene within a genome, they don't know how it interacts with other genes and the environment. Not all people experience a disease or condition associated with the presence of a gene. Additionally, governments and civil societies haven't adequately looked at the social implications of decoding individual and collective genomes.

Reardon challenges the belief that "good science and the good society are made together" by citing examples to the contrary, describing a fundamental asymmetry in the United States and other countries between research and public benefit. For example, when genetic researchers went to the Black Belt in the southern United States to talk about potentially beneficial genomic research in the early 2000s, they encountered the response that genetics "is not important because there is so much else wrong" and were met with community requests for hospitals and better health care. These needs are much more proximate in marginalized communities than genomic advancements. Why participate in a genomics study when your local community doesn't have the basic necessities to provide you with adequate health care in the first place?

I find her critique of the "faster, better" mechanization of decoding human genomes only partially compelling. This critique reads more like the Luddite lament of a former lab scientist than the analysis of a major problem. But she's right to suggest that a preoccupation with the speed of decoding—when we don't know how to interpret the vast majority of the data we already have—may shape the industry's aggressive attempts to sell genomic services.

Written with an academic audience in mind, this book is well suited for those interested in bioethics and scientific communication. It generates more questions

than answers about the postgenomic condition, including: “How can public dialogues link to policy change?” and “What is the relationship between innovation in science and technology and inequality?” While Reardon is not prescriptive about what the future looks like for the use of genetic information, she clearly thinks that justice should be a central organizing principle for institutions as they work with individuals and communities to collect and use genetic data. Reardon equips readers to thoughtfully question the Silicon Valley hype about personalized genomics that constantly bombards us.