

Digital artwork created from DNA.

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BIOETHICS

Justice in genomics

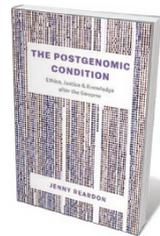
Rosario Isasi examines a study on the societal impact of grand sequencing projects.

Jenny Reardon's *The Postgenomic Condition* aims to reconcile innovation in genomics with justice and democracy. Looking at two decades of genomics advances, she asks hard questions about whether developments such as personalized medicine have had a truly democratizing impact. Reardon uses worst-case scenarios to demonstrate the complexities of human genomics and bioethics in the broader sociopolitical and global context. These are science stories construed as cautionary tales, strategies for anticipating, managing and mitigating risks.

Reardon, a sociologist at the University of California, Santa Cruz, draws on more than a decade of fieldwork in start-ups, labs and government agencies for her robust and enlightening analysis of the Human Genome Project (HGP) and its aftermath. She covers its broad societal impact, from wider inclusion of minorities in research to the expansion of rights and obligations arising from sharing human samples and data. The titular postgenomic condition, she argues, began when genomics became a focus of “turn-of-the-millennium hopes for justice through data and democracy”. With the emergence of a genomics that was “participatory, inclusive, and open”, sequencing data acquired

meaning and value.

Her narrative begins in the early 1990s. The HGP was followed by the launch of other efforts, including the Human Genome Diversity Project, the International HapMap Project, the Icelandic company deCODE genetics and Generation Scotland, a national biobank of donated tissue. Reardon chronicles the rise in the 2000s of personal-genomics projects and companies, such as 23andMe, the Personal Genome Project, the medical-data-sharing initiative Open Humans and the world of do-it-yourself biology, including the community DIYbio.org. Thus, she traces the shift of genomic research to a more participatory and diverse venture that ultimately transformed conceptualizations of self-governance and privacy. Open-consent models, for instance, have changed the agency of consent “from what individuals let researchers do to their data to what individuals do with their data”.



The Postgenomic Condition: Ethics, Justice, and Knowledge After the Genome
JENNY REARDON
University of Chicago Press: 2017.

Reardon lays out a bold vision for genomics's potential. She probes the value of the human genome from a utilitarian perspective, contending that human DNA and data constitute the raw resource of our times: a commodity whose value is to be quantified as biocapital. Thus, the postgenomic condition is about using information and knowledge as the currency from which to build a “genomics that is of, for, and by the people”.

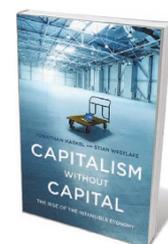
She argues, however, that reality so far does not match that aim. She says that she doesn't want to cast players as heroes and villains, but she does — albeit skilfully and with considerable nuance. She suggests, for instance, that a free society profiting financially from the DNA of its citizens leads to “the corporate corruption of science”. For her, genomics is an arena in which the aim of understanding human diseases vies with the aim of settling “disputes over property, identities, and resources”. Reardon highlights the tensions between inclusion and exclusion, transparency and obscurity, freedom and control — and, finally, integrity and public interest.

She starkly criticizes the US Precision Medicine Initiative, a long-term, large-cohort study led by the US National Institutes of Health to develop prevention and treatment strategies that

ECONOMICS

How science got a golden ticket

Ehsan Masood hails an account of the mixed implications of governments valuing research as an investment.



Capitalism Without Capital: The Rise of the Intangible Economy
JONATHAN HASKEL & STIAN WESTLAKE
Princeton University Press: 2017.

because much twentieth-century economic activity pivoted on industrial manufactured goods such as processed food, aircraft, cars, pharmaceuticals and weapons, all of which could be bought and sold for a price.

But the companies that made these goods — the Krafts, Fords and Raytheons — have since been joined by the likes of Amazon, Airbnb and Uber. And these ‘new economy’ companies have astronomical valuations. The problem is that national statistical offices from Chile to China have yet to agree on how all that these firms do should be reflected in gross domestic product, or GDP.

There are several reasons why this absence of what Haskel and Westlake call “intangibles” matters. Politicians, the markets and the media obsess about GDP figures. Political careers can rise or fall in tandem with them. Moreover, across the United States and Europe, and especially after the crash, the rate of GDP growth has been underwhelming; between 2010 and 2016, US GDP, for instance, rose by just 2.1% per year. If the figures are failing to account for one of the richest and fastest-growing economic sectors, then it is probable that the rate of economic growth is being underestimated. That alone is likely to be an incentive for governments to accelerate incorporation of intangibles into GDP.

Some intangibles, however, face bigger battles than others before they are likely to find a home in the GDP tent. Published ▶

factor in individual variability in genes, environment and lifestyle. She views it as a public-relations approach to managing research participants, offering what might seem innovative ideas to “make them want to comply”. She delves, too, into complex cases such as that of Henrietta Lacks, whose cervical tumour was used to create the HeLa cell line without her consent (see *Nature* <http://doi.org/kzq>; 2013).

The book concludes with a vague proposal for a national commission to revisit the 1979 Belmont Report, the US federal report on ethical guidelines for research involving humans. Although Reardon’s personal approach to the narrative is appealing, she only sparsely addresses the sociocultural and historical factors that shape genomics initiatives, and largely leaves out any analysis of the national policy frameworks that govern them. Her frequent reliance on political theory, particularly the works of Hannah Arendt, could also render the book inaccessible to a wider audience.

Reardon’s underlying message is one of disappointment. She believes that genomics has enormous beneficial potential, but sees the human genome as a currency that so far has been deprived of value because, she alleges, of a lack of medical breakthroughs resulting from it. This is the major shortcoming of the book. As a storyteller, Reardon neglects narratives in which the value and transformative power of genetic discoveries have already accrued.

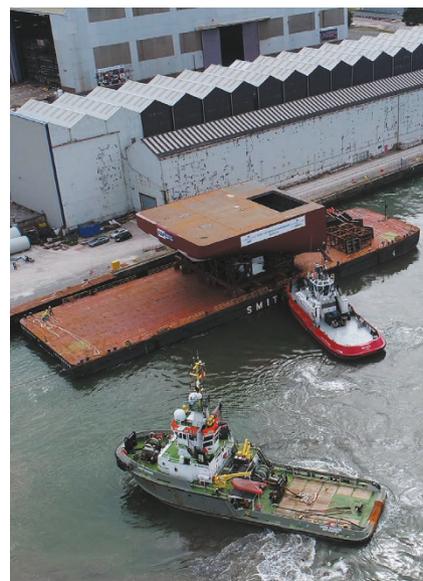
We don’t hear of successful screening programmes for newborns, or emerging gene or cancer therapies such as those for spinal muscular atrophy or Duchenne muscular dystrophy, sickle-cell disease or leukaemia. We don’t hear about initiatives that have already had an immense impact in the diagnosis or treatment of rare and intractable conditions — such as those for lysosomal-storage disorders or congenital myasthenic syndrome. Also absent are voices of people who are affected by genetic disorders, or who work at the interface of clinical care and research, where the meaning of the human genome is continuously emerging. In my view, had we heard from these actors, the answer to Reardon’s core question — what is the value of the human genome? — would have been powerful and unequivocal. The human genome has an ineffable value. ■

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Any researcher whose eyes glaze over at the phrase ‘national accounting’ should heed this tale. In the years since the financial crisis of 2008, Britain’s science budget has been protected. While libraries shut, children’s services shrank and nurses and teachers saw real wages fall, science spending has held steady. Why? Because successive finance ministers have been persuaded that cutting science, unlike cuts to other forms of public spending, would jeopardize the nation’s future economic growth.

Notwithstanding the contested ethics for such a choice, chancellor George Osborne, one of these ministers, was able to protect science spending partly because of a seemingly arcane rule change by the UN Statistical Commission, implemented in Britain in 2014. Research and development had been recategorized as an investment rather than a cost, gifting science the golden ticket of future budget increases.

This is one tale told in *Capitalism Without Capital*. Economist Jonathan Haskel and UK government adviser Stian Westlake describe in an entertaining and engaging way why governments need to count innovation as an engine of profit. The authors also make



Construction of a new polar research vessel funded by the UK government.