

## Justice and solidarity in post-genomic, personalized times

Review of Prainsack, Barbara. 2017. *Personalized Medicine: Empowered Patients in the 21st Century?* New York: New York University Press, pp. 271 & Reardon, Jenny. 2017. *The Postgenomic Condition: Ethics, Justice & Knowledge after the Genome*, Chicago: University of Chicago Press, pp. 311

If there is one promise that has shaped biomedicine in Euro-America in the past two decades then surely it must be the promise that we are on the cusp of a more precise, targeted, tailored and personalized medicine made possible by global terabyte-data infrastructures and high-power computing. As Barbara Prainsack points out, personalization in medicine has been driven by “the data-intensive characterization of individuals at different stages of health and disease in the course of their lifetime” (p.4). By now, this data can include an individual’s whole genome, biomarker measurements derived from biological samples, bodily scan images, vital measurements, lifestyle records as well as self-reported moods, health states and/or symptom experiences. What is more, the increasing merging of smartphone technologies with social media platforms through a growing repertoire of apps is enabling ‘real time’ collection of personal data on physical activity, sleep patterns, moods, drug side effects, vital signs and more.

What we learn from reading Jenny Reardon’s *The Postgenomic Condition* and Barbara Prainsack’s *Personalized Medicine* (both from 2017) in tandem is that, in bringing high-power computing to these exponentially growing data sets, medical practitioners have set their sights on detecting and identifying in more targeted ways those who are: 1) genetically predisposed to certain diseases or conditions; 2) at risk of certain diseases or conditions because of their lifestyle; 3) already sick without having experienced any symptoms; 4) likely to respond better to particular pharmaceutical treatments or conversely to suffer from more toxicity; and 5) are not complying with prescribed therapeutic regimens.

Hence, I would suggest that it is to the dual temporalities of disease predisposition and inclination on the one hand, and treatment response and compliance on the other that personalization and precision are directed. Pre-disease temporalities are organized by an ‘inevitably-ill’ logic (i.e. the expectation that if not already, everyone is on their way to becoming ill) in which data-intensification can help us either prevent or detect illness as early as possible while illness-temporalities are ordered by a logic of treatment-optimization where data-intensification is needed to target medicine and ensure adherence to prescribed regimens. These logics are, in turn, driven by respective promises of maximizing the number of well years or healthy years a person has in her or his lifetime (prevention) and of providing the best possible treatment if and when he or she falls ill (early detection and tailored treatments). At stake are both the length and quality of life for all.

In recent years, numerous social studies of regenerative medicine (Bharadwaj 2012), genomics (Rajan 2006) and neuroscience (Rose & Abi-Rached 2013) have shown how hype and hope are mobilized by scientists, policy makers, patient associations and biotech companies alike to generate visibility, raise venture capital and/or secure government funding. Since similar mobilizations are, without question, currently forming around personalized medicine, Reardon’s and Prainsack’s monographs are urgent reminders of how crucial socially informed empirical analyses of biomedicine are at a time of globally unprecedented health inequality, intensifying commercialization of health care and troubling encroachments on individuals’ and families’ rights and privacy. Indeed, for Reardon, the “postgenomic condition” is animated by “questions about the just constitution of meaning and value after the human genome, after the world financial crisis and in the midst of a data deluge and eroding trust in dominant institutions” (p.14). Taking aim at the promises of patient empowerment and patient value that have propelled genomic and personalized medicine agendas in Euro-America especially, Reardon and Prainsack show us how notions of solidarity and justice can be powerful allies in contemporary efforts to rethink biomedicine in ways that make it relevant to the people who need it throughout the world.

### *Damp squibs or future proofing?*

When reflecting on the global emergence of genomic science in the 21st century, a number of initiatives stand out – e.g. the Human Genome Project (completed in 2003), the International HapMap project, deCode in Iceland and 23andMe. Likewise, when it comes to the intensification of personal health data collection, PatientsLikeMe, CureTogether and numerous Electronic Patient Record systems from around the world, come to mind. These and other similar initiatives serve as a series of case studies for both Reardon and Prainsack. Their books are methodologically aligned as well. Both scholars have carried out multi-sited ethnographic research involving attendance at specialist conferences, expert interviews, and collection of website documents, media reports and scientific papers. At the same time, their studies do diverge. For example, in their respective analyses of 23andMe Prainsack pursues an analysis of the consequences of data intensification for patients, whereas Reardon explores the valuing of genomic science from the perspective of researchers.

Importantly, what the respective analyses of the initiatives covered in the two books have in common are a set of overhanging questions as to their actual value. Have PatientsLikeMe, Generation Scotland or the International HapMap project generated any actionable findings, which can or have been used to prevent disease, detect it earlier or treat it better? Or are they instead data-generating infrastructures which need to be maintained such that actionable findings will be possible in an unspecified future? The answer for both authors seems to be that while there certainly have been advances made in the fields of personalized medicine and genomics, these advances are nowhere close to constituting a revolution or paradigm-shift within medicine. The heralded Common Disease-Common Variant (CD-CV) hypothesis has not lived up to expectations nor are most people in the world plugged into the infrastructures that support data-intensification through the amassing of personal health records electronically over time. Moreover, Prainsack demonstrates in her problematisation of apparently democratizing ‘patient-led’ research initiatives, that they are often governed by companies who profit

from the labour of those patients who voluntarily keep online symptom diaries and share their treatment experiences. Reardon shows how Generation Scotland's strategy of mobilizing public support by appealing to citizens' sense of national pride ended up impeding its ability to capitalize on its amassed biological resources. Since samples were meant to 'stay in Scotland' genome sequencing costs ended up being substantially higher than in places like China, England or the US.

The sense one is left with after reading *Personalized Medicine* and *The Postgenomic Condition* is that while data intensification is growing in a massive way, it is not yet clear how the resulting data sets in the form of biobanks or patient-reported symptom and treatment diary databases are best curated, maintained and mined. Indeed, as Reardon points out (pp. 139-40), in many ways it is curation which gives these data sets both economic and scientific value as it is the curators who maintain, clean up and standardize data sets so as to make them as efficiently and practically mineable as possible.

#### *Euro-American differences*

The development of personalized medicine is arguably playing out in significantly different ways in the USA and Europe (not to mention within different European countries). Most notably, European national health insurance systems are very different from the private health care insurance systems that operate in America. Also, privacy laws differ not least following the recent introduction of the European Union's General Data Protection Regulation (GDPR). In their analyses, both Reardon and Prainsack tack back and forth between Europe and the USA, however, the comparative potential that emerges from their case studies remains underdeveloped in both books.

Building on many years of work, Prainsack defines solidarity as a set of practices through which "people or groups express their willingness to accept 'costs' to assist others with whom they recognize similarity in a relevant respect" (p.152). And for Reardon, (social) justice is a matter of allocation, distribution, sharing and equity. For both, the question of who will benefit from genomics and

personalization through data intensification is at the fore. Yet, clearly, both solidarity and justice have their particular forms in Europe and America respectively. Prainsack argues that personalized medicine “requires more solidarity, not less” (p. 177) and calls for universal and affordable health care as a consequence. However, given that this is unlikely in the USA at this point, the question is whether other forms of solidarity are imaginable and indeed whether solidarity is at play at all in an American setting.

In a similar vein, European and American approaches to justice have very different political economies and histories: social justice in Europe has broadly speaking rested on state-led forms of redistribution and reallocation while libertarian justice in the USA has valorized ‘equality before the law’ underpinned by litigation. It would have been interesting to hear Reardon’s and Prainsack’s thoughts on how, for example, UK Biobank, Generation Scotland and Electronic Patient Records within the NHS in the United Kingdom *differ* from 23andMe, PatientsLikeMe and the stratification of healthcare insurance plan members using big data in the USA. While each of these initiatives has been made possible by data intensification, the shaping of data intensification trajectories are markedly different in Europe and America (cf. Cool 2016; Hogle 2016). Given these particularities, how different are Prainsack’s figures of “the patient researcher”, “the self-tracking patient”, “the participating patient” or “the prosumer” in Europe and America respectively?

*Who benefits?*

The troubling question that lingers after reading Reardon’s and Prainsack’s social studies of personalized medicine and genomic research is whether and to what extent promises of justice and empowerment lie in tatters in the age of the sequenced genome and big data. Is it the patient who will benefit from being categorized? Or is it rather the genomic scientists whose careers are boosted, the high throughput genome sequencing companies, the healthcare insurers who introduce physician pay-for-performance schemes or the online companies who source and exploit user-generated data?

Prainsack and Reardon it seems would point to the latter and I would tend to agree. Still, Prainsack very helpfully throughout her book summarizes how she believes that a better personalized medicine can be pragmatically fostered by insisting that it indeed is the patient who *should* benefit from the possibilities that data intensification is bringing in its wake. This will not be achieved in and by itself, rather it will require appropriate regulation and relentless efforts from activists, policymakers and social scientists to ensure accessible and affordable healthcare for all.

In an American context, Reardon's stark reminders of how stratified healthcare in the USA remains as one of the greatest obstacles to justice should be read as a call to arms. I would recommend reading her book alongside Kim TallBear's *Native American DNA* (2013) and Alondra Nelson's *The Social Life of DNA* (2016). Taken together, these three books show us how critical scrutiny of genomic research agendas can shed light on contemporary racial politics. Even if a genomic revolution has failed to materialize within medicine, the effects of genomic research reverberate around the world among the communities whose DNA is sought to learn more about human disease and history.

## References

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