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REVIEW

Justice and Solidarity in Post-genomic, Post-personalized Times

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If there is one promise that has shaped biomedicine in Euro-America in the past two decades then it is the promise that we are on the cusp of a more precise, deep, targeted, tailored and personalized medicine, made possible by global data infrastructures and high-power computing. Whether in the form of bioinformatics, ‘real-time’ pandemic epidemiology, high throughput drug development, electronic patient record systems or artificial intelligence health algorithm analytics, information technologies are pursued by investors, policymakers and healthcare providers alike as the next frontier in medical advance. In policy terms, the personalized medicine agenda is very often tied directly to heavy investments in genomic science and the search for treatments based on a patient’s unique genetic make-up, although it might be argued that clinicians have always been tailoring treatments to the individual characteristics of their patients using their skills and best available evidence. Whether in China or Denmark, national governments have pursued and funded National Strategies for Personalized Medicine, raising numerous questions for science studies scholars about the ways in which hypes and hopes continue to shape biomedical research, the unintended consequences of big-investment research agendas as well as emerging ethical issues in relation to the capturing of personal data and potential asymmetries in care provision.

Though there are many different agendas under the umbrella of personalized medicine, Barbara Prainsack argues that, in recent years, this push toward personalization has been driven by ‘the data-intense 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 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.

At a time where healthcare data collection and surveillance are intensifying by the day, not least as part of national responses to the COVID-19 pandemic, Jenny Reardon’s *The Postgenomic Condition* and Barbara Prainsack’s *Personalized Medicine* (both from 2017) stand out as important critical contributions to the social study of what Klaus Høeyer (2019) has termed ‘data as promise.’ In Reardon’s and Prainsack’s monographs, we learn how high-power computing and exponentially growing data sets are being leveraged to segment populations into ever more differentiated groupings. In my

reading of Prainsack and Reardon's analyses, the following population segments are at the core of efforts to make medicine more precise: (1) those who are genetically predisposed to certain diseases or conditions; (2) those who are at risk of certain diseases or conditions because of their lifestyle; (3) those who are already sick without having experienced any symptoms; (4) those who are likely to respond better to particular pharmaceutical treatments or conversely to suffer from more toxicity; and (5) those who are or are not complying with prescribed therapeutic regimens. This focus on disease predisposition and disease inclination on the one hand, and treatment response and compliance on the other seems to produce two distinct logics: first, a logic of inevitable morbidity (an expectation that if they are not already, everyone is on their way to becoming ill and therefore their disease signals should be 'caught' as early as possible), and, secondly, a logic of treatment-optimization (requiring the timely identification of treatment-responders as well as those most likely to suffer from toxicity in order to target specific therapies). 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 when he or she falls ill (early detection and tailored treatments).

In recent years, numerous social studies of regenerative medicine (Bharadwaj, 2012), genomics (Rajan, 2006) and neuroscience (Rose and 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 2008 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 proponents have used to propel 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?

The global emergence of genomic science in the twenty-first century has been led by a number of initiatives like the Human Genome Project (completed in 2003) and deCode in Iceland. Likewise, PatientsLikeMe, CureTogether and numerous Electronic Patient Record systems from around the world, are central to the intensification of personal health data collection. These and other similar initiatives serve as a series of case studies for 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 medical, economic and social value for patients and society. Have PatientsLikeMe, Generation Scotland or the International HapMap project generated any actionable findings that 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 is clear: 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. This is not least since, as Lukas Engelmann wrote recently in this journal in his review of Eric Topol's *Deep Medicine* (2019) 'a division of pathological and normal states can never be cleansed ... of an individual's physiological experience within their milieu' (Engelmann, 2020). For example, the much-heralded Common Disease-Common Variant (CD-CV) hypothesis which suggested that it would be possible to find specific variants linked to specific diseases through genome wide association studies has not lived up to expectations nor are most people in the world connected into smartphone and PC-based infrastructures that support data-intensification. Moreover, Prainsack demonstrates in her problematisation of apparently empowering 'patient-led' research initiatives, that they are often governed by companies who profit from the labor of 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. 139–140), in many ways it is curation which gives these data sets both socio-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 has, arguably, played out quite differently in the USA and Europe (not to mention differences within Europe). This is partly because 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.

Take for example the way each author deals with political potentials in these two contexts. Drawing on her previous 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. 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 in time, 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 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 where justice is meted out through lawsuits. 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 health insurance industry in the USA. While each of these initiatives has been made possible by data intensification, the shaping of data intensification trajectories is 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?

Several troubling questions linger after reading Reardon’s and Prainsack’s studies. To what extent do promises of justice and empowerment lie in tatters in the age of the sequenced genomes and big data? Is it the patient who will benefit from being categorized? Or is it rather the genomic scientists, the genome sequencing companies, the healthcare insurers or the online companies who source and exploit user-generated data? Prainsack and Reardon it seems would point to the latter set of beneficiaries and I would tend to agree. Still, Prainsack 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 by itself, rather it will require appropriate regulation and relentless efforts by healthcare practitioners, activists, policymakers and social scientists to ensure accessible and affordable healthcare for all.

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). Each of these books show us how critical scrutiny of genomic research agendas can shed light on contemporary racial politics and the uneven ways in which benefits accrue. 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.

As the COVID-19 pandemic continues to lay bare and amplify scandalous health inequalities both within countries and between countries of the so-called global North and South, we are reminded of the millions of people who die from entirely treatable disease. For these people and their families, the promises of a personalized medicine remain hollow. Reardon and Prainsack’s books thus offer a timely reminder of the importance of considering the future of healthcare as beyond the ‘personal.’ At a time

where COVID-19 is overwhelming healthcare systems around the world as well as disproportionately affecting minority groups – either as casualties of the virus or as those ‘essential workers’ who are providing care and services during lockdown – what is needed is a new politics of health, built up around social justice and solidarity instead of personalization and individual responsibility. Through their meticulous research on one of the most hyped biomedical research agendas in recent times, Reardon and Prainsack demonstrate the critical value of ethnographically informed social studies of science as it unfolds in laboratories, clinics and policy arenas.

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