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To cite this article: Alexis Walker (2022) Diversity, Profit, Control: An Empirical Study of Industry Employees' Views on Ethics in Private Sector Genomics, AJOB Empirical Bioethics, 13:3, 166-178, DOI: [10.1080/23294515.2022.2063993](https://doi.org/10.1080/23294515.2022.2063993)

To link to this article: <https://doi.org/10.1080/23294515.2022.2063993>



Published online: 18 Apr 2022.



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Diversity, Profit, Control: An Empirical Study of Industry Employees' Views on Ethics in Private Sector Genomics

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ABSTRACT

Background: Large amounts of capital are currently being invested in genomics companies across the “bench to clinic pipeline” – companies which are now shaping the future of biomedicine globally. Understanding the perspectives of people who work in such companies can contribute to shaping this industry in service of just and equitable futures of medicine.

Methods: Using in-depth interviews as the primary method, this paper analyzes perspectives on ethical and social issues in private sector genomics expressed by members of the commercial genomics industry in the US.

Results: Interviewees described a wide range of issues as pressing ethical concerns in commercial genomics. Key themes included concerns about diversity in genetic datasets, data governance and control, and pricing and profits in the industry. However, concern about diversity of datasets was not accompanied by expressions of concern about diversity in the industry workforce.

Conclusions: Most interviewees described concerns in the industry that are rather removed from their own work. But along with this “ethical distancing,” moral concerns appeared to be the basis for competition amongst companies – to attract both employees and customers. Research in business ethics suggests that expanding moral analysis of one’s own work helps improve day to day decision-making in the interest of justice. Opening space for people to examine ethics in their own subsector may provide a means for the private sector genomics industry to become a leader in ethics in the biosciences and a model for equity in our current moment of late capitalism.

KEYWORDS

Ethics; genomics; industry; interviews

Introduction

Prior to its \$8 billion acquisition in fall 2020, the cancer genomics startup GRAIL had already raised \$2 billion from private investors for research and operations on its early cancer detection tests – double the total annual funding for all cancer genomics research by the US National Institutes of Health (National Institutes of Health 2021). From companies like California-based GRAIL that are developing tests of freely circulating nucleic acids in blood (in order to improve diagnosis and disease monitoring), to companies using artificial intelligence to mine genomic data to identify promising drug targets (e.g., Canada’s Deep Genomics), and companies building genetic databases and analysis support (e.g., WuXi NextCODE) – privately and publicly held companies are now the site of much of the world’s research in genetics and genomics.

Companies working on genomics are designing and developing the next generation of diagnostics and therapeutics – determining which disease areas to focus on, which patient types, as well as pricing, etc. This includes both startups focusing on genomic technologies as well as established pharmaceutical interests.¹ The day to day decisions of employees and leadership in these genomics companies will strongly shape the distribution of benefits and access in the future of biomedicine. And while research on ethical, legal and social issues in private sector genomics has highlighted important risks in companies’ marketing and sale of products (Lee 2013b, Wagner et al. 2012, TallBear 2014), as well as (potential) users’ perspectives on direct-to-consumer (DTC) genetic testing (McGuire et al. 2009, Goldsmith et al. 2012), ELSI research has not much focused on investigating views from individuals working within the industry itself. But understanding which ethical and social issues

people working in such companies think and talk about, and the ways they do so, is a key to understanding the possibilities for advancing justice in and through private sector genomics; this baseline perspective is crucial to creating steps toward greater equity – for continuing to push debates and norms in this sector toward ever greater standards of justice.

This paper presents results from an interview study with leadership and employees of US-based genomics companies, investigating their perspectives on the social and ethical dynamics of their work, and the frameworks that guide their thinking.

Methods

This analysis is based on semi-structured interviews with members of the private sector genomics industry in the United States, conducted between October 2019 and December 2020. This includes companies across the “bench to clinic” pipeline (from companies developing sequencing technologies to therapeutics) and across sizes/stages (from early stage startups to late stage, established industry players). This interview study is part of a broader multi-methods study that includes both ethnographic and survey research; interviews serve as one contribution to investigating ethical concerns and viewpoints expressed by members of the private sector genomics industry.

Interviewees were identified through a combination of purposive and snowball sampling (Tracy 2013, Etikan, Musa, and Alkassim 2016) in order to map a full range of concerns and the reasoning behind them, with attention to people in positions of influence – whose decisions most strongly impact ethically relevant outcomes. The study sample is thus primarily composed of company senior leadership, in positions focused on bio- and data science, as well as business development. Interviewees were recruited until reaching saturation (Tracy 2013).

The interview guide opened with initial questions about the interviewee’s personal and professional background, leading to broad questions about issues of concern in genomics today (“Are there areas in genomics today where we ought to be careful?”), before asking more specifically “What do you see as the most pressing ethical and social issues in your work and in the industry today?” This combination of questions was meant to help identify issues of concern to interviewees, as well as the specifics of how they understand the category of ethics in their work/field.

An initial set of fourteen interviews were conducted in person in San Diego and the San Francisco Bay

Area between October 2019 and February 2020. Based on continued progress of the Covid-19 pandemic, the final twenty interviews were subsequently conducted by video conference. Interviews were audio recorded by permission of each participant, and transcribed by a professional service under strict confidentiality procedures. While some participants welcomed the research team to cite them by name, participant names have not been included here. This study was approved by Institutional Review Boards at both Johns Hopkins University and Columbia University.

Interview transcripts were coded based on recursive engagement – reading and re-reading transcripts while developing thematic lines (Glaser 1965).

Results

Thirty-four participants were interviewed before reaching saturation, at which point new interviews were not yielding new themes. Participants listed a wide range of issues as “the most pressing ethical and social issues in private sector genomics today.” The most prevalent themes were: 1) diversity within genetic datasets, 2) data management and governance, and 3) price and profit, further described below.

Participants also expressed concerns regarding human germline gene editing (the possibility of off-target effects, risks of attempting to enhance humans beyond a normal range of function, approaches that stigmatize disability by treating characteristics such as deafness as something to be edited away rather than a rich aspect of human diversity), racial and other disparities in access to genomic medicine (e.g., access to genetic testing, diagnostics, therapeutics based on unequal health insurance coverage and barriers to care such as transportation, location of health-care facilities, racial inequality in referral and medical care more broadly), and police use of public ancestry databases (e.g., privacy and invasive state control by identifying family members of people who have shared genetic data through 23andMe and other consumer genetic databases).

Additional concerns included transparency and the sale of tests that are not rooted in robust research. On the former, concerns arose regarding: 1) “hyping and burying” information in the interest of managing stock prices and company valuations, 2) pricing transparency (e.g., how much hospitals and insurance companies are paying for products and procedures), and 3) providing evidence to support company offerings. On the lack of data supporting some tests on the market, some participants argued that “entertainment” tests (e.g., an oft-cited test for genetics and wine

preference) are not a huge concern, but others argued these tests do a major disservice in sending erroneous messages about what genetic information can really reveal, and this in the interest of profit.

Less often-cited issues included explicitly fraudulent behavior (e.g., data manipulation) and exploitative research recruitment, as well as insufficient attention to the nuances of sex and gender – notably the ways that cultural assumptions about gender limit reproductive options, including for people with sex chromosome aneuploidies.

And while interviewees consistently cited diversity in genetic datasets as a major issue of concern, far fewer interviewees expressed misgivings about the current state of diversity in the industry itself. The only interviewees to raise this latter issue spontaneously were people of color themselves, several of whom emphasized the need for better representation of people of color across functions in the industry – from research and product development, to marketing, engineering, and business development. These participants argued that, while it is important to improve the “pipeline” of diverse people choosing education and careers in these areas, there are many qualified people of color in the workforce currently; these participants emphasized the importance of recruitment and retention efforts, including recognizing candidates of color as leaders and decision-makers in the first place. One self-identified Black bioscience lead stressed, “there’s plenty of talent and I know them; they’re my friends, they’re my peers” (Participant 33).

Interviewees expressed keen awareness of public concerns regarding ethics in their industry, including concerns that they hear from their own family members – largely regarding profit and the sale of users’ data (e.g., by genetic testing companies to pharmaceutical companies). However, several also noted that the term “ethics” has become associated with boring trainings that present a demand on their time without much real insight, or associated with massive abuses and fraudulent behavior rather than day to day advancement of justice.

Diversity in genetic datasets

Just under forty percent of participants spontaneously cited a lack of diversity in genetic datasets as a top issue that concerns them in commercial genomics. Many respondents stressed that for members of “underrepresented populations” today’s biomedicine can offer less certainty about the meaning of our genes, as there is a lack of data showing similar

genetic backgrounds and variants against which to compare.

Participants varied in whether they described this as a lack of *racial* or *ancestral* diversity in datasets. Focusing on ancestry, one senior geneticist working in a biopharmaceutical company argued:

It is incredibly stupid scientifically to focus entirely on a narrowly ancestrally defined group that represents a small fraction of the possible perspectives...we should be looking all across a spectrum and the way we’re doing that...is we’re trying to partner with people who have collections of very ancestrally diverse samples...looking at founder and bottleneck populations, which are like the Amish in Pennsylvania, people on the Faroe Islands... (Participant 19)

This participant emphasized the importance of sampling across ancestral populations—not just continentally-defined populations, but smaller groups whose histories of migration, isolation, rapid population decrease, etc. lead to genetic variations and backgrounds distinct from other populations. So while white Americans have been heavily sampled in biomedical research, and the Amish might be *racially* categorized as such, they are a bounded population historically; ancestral diversity is far from coterminous with race, this participant explained. This understanding shapes how his multi-billion dollar company approaches investigation of new therapeutic avenues: they focus on expanding diversity of their study samples in terms of ancestral micro-populations (not racial groups) in order to better identify biologically significant genetic variants that could be therapeutic targets.

Other interviewees expressed concern about diversity of genomic datasets by using language focused on race. A leader in pharmacogenomics emphasized her top concern in genomics currently:

one of the things that I’m sure is concerning to everybody in genomics is that there’s a lack of diversity in genetic information. I think everybody’s very aware of that. Virtually all of the pharmaceutical trials are white males. Virtually all of the genetic information is Caucasian data. They’re working to expand that, but it’s still— a lot of the variants of unknown significance for genomics widely, it’s a lot higher in underrepresented races and ethnicities than it is in Caucasians. (Participant 24).

This director-level expert in a major genomics company emphasized race as the key genetic variable for diversity concerns. Following a similar logic, when asked about whether this diversity concern ought to be considered in terms of race, the Director of

Genomics at one biopharmaceutical company argued “technically, if you look at your gene sequences, it will decipher you by race as well as ancestry. So I mean it is what it is” (Participant 26). This hazy language avoids the question of how racial categories ought to be used in genomics research, but also implies that race is a biological fact that one cannot avoid.

Participants varied in how much they argued is being accomplished of late to ameliorate the lack of diversity in genetic datasets. While many participants suggested that this is a priority issue that is receiving a great deal of attention in the industry, one senior scientist in a population health company emphasized:

It’s actually a pretty hard problem, but there’s not a whole lot that’s changing to make a significant difference...what we’ve seen with genomics is that we’re measuring small effects, so we need large numbers, and to do large numbers recruiting is dramatically difficult, and guess what? It’s much easier to recruit people that are already in the health system... (Participant 4)

This participant argued that, although the importance of diversity in genetic datasets is well-recognized, the reliance on recruiting people who are already in the health system, in a country with very unequal access to care, leads to persistent inequities in recruitment and resulting participation. But out of all interviewees noting concern about diversity in datasets, only one (the Chief Medical Officer for a genetic testing company) named this as rooted specifically in *racism* per se:

[there is] an inherent unfairness in the medical care system of who gets tested and who doesn’t. And I think some of it comes from the very still persistent...belief that genetics is esoteric...It’s something that people who have disposable income can worry about...but that your lower middle class and the lower class socioeconomic status, you’re worrying about getting food on the table. You’re worrying about getting your kids safely through school when you’re worried about COVID-19 or whatever. And so the idea that less economically advantaged people are not just as devastated by children with severe genetic disorders, are not just devastated by BRCA mutations, there’s kind of a fundamental racism in it (Participant 26).

This participant linked socioeconomic inequality and racism in American medicine, arguing that an important driver of the lack of diversity in genetic datasets is racial inequality in who is offered and expected to desire genetic testing.

Data governance and control

Participants also expressed substantial concern about how genetic data are being managed, especially with regards to data sharing and sale. Many participants argued that there is a moral responsibility to make good use of all existing genetic data, which they suggested requires broad data sharing – allowing as much knowledge as possible to be extracted from this data, through research access by as many responsible parties as possible. Citing these concerns, participants critiqued practices of exclusive data control by individual companies, arguing that many companies “lock up” data so that they’re able to have a competitive advantage. One genomics lead in a biopharmaceutical company stated:

different companies have different philosophies. Some see a considerably higher return on investment when they are doing these activities by locking the data for either an indeterminate amount of time or a certain exclusivity period ... or you can say buying entire countries. You know...where you have just one company sponsoring an initiative with this being all of an entire country...with deCODE or Amgen... (Participant 17).

This participant linked data sharing with concerns about individual companies having sole access to national databases, as in Iceland or Ireland, where public funds and governmental relationships were used to create genetic databases from the population, which have then been licensed exclusively to individual companies.

While some participants suggested that exclusive rights to genetic data should be regulated, several also expressed concern that current privacy regulations hinder data sharing, without actually providing much privacy protection. Many were concerned about *balancing* privacy protections with research access, which they framed as an ethical imperative, and several offered technology (rather than regulation) as the key to protecting privacy.

Several participants criticized the way that companies are profiting at the expense of individual control over one’s own genetic data. The CEO of a prominent genetic testing company argued:

to me it is shocking how...if a patient shows up at a hospital, the hospital assumes they own their sample and their information. Most of the large laboratories in the world sell...their patients’ data...to these anonymized aggregators that’re then selling it back to pharma, Nestle, Unilever, credit card companies, what have you... (Participant 27)

While a great deal of attention has been paid to the sale of users' genomic data to pharmaceutical companies by direct-to-consumer genetic testing companies, this CEO highlighted hospitals as a key player that have been selling patients' genomic data without real participant understanding, emphasizing the role of "anonymized aggregators" in making it harder to identify the sale of data to interests that might otherwise raise public concern. He argued that meaningful patient ownership and control of personal data will be a key allowing genomics in the private sector to advance.

Several participants framed data privacy and control as crucial to their companies' identities. One CEO argued, citing the European Union's General Data Protection Regulation (GDPR):

data privacy is essential to what we do...I think that, in general, the current system is unfair, because you give your data to the company and if the company makes money, you don't participate ... I want to be not only GDPR-compliant, I want to be beyond that... we want to be the standard. So, do not [collect] the data that you don't need, that's it. (Participant 22)

This biotech expert framed corporate profit as a problem when it isn't met with participant financial benefit, and he situated himself and his company as an answer to these challenges, arguing that data privacy can be a market differentiator that brings companies success, above and beyond regulatory approaches. For him, limiting the kinds of data the company collects is a key privacy protection.

While many interviewees emphasized the importance of participant control over personal data, some interviewees also emphasized the need for approaches to data use that do not depend on participants having to take such an active role to protect the use of their data. One company co-founder argued:

you look at the...flat-out earned mistrust...especially with understudied populations, I do think we need to have better constructs around privacy and consent. Guardrails on what the data can be used for. We have to get less squishy about "it'll be used for research"... What kind of research? Whose kind of research? Whose idea of ethical research? (Participant 2)

This CEO argued that data use should be managed to protect the interests of the most marginalized, and should be more transparently disclosed to users. She went on to emphasize that the genetic database her company is building will not be used for research on

sexual orientation or incest – issues that may lead to group harms through stigma, and that are not "health-related" in her view.

Price and profit

Almost a third of interviewees, in considering top concerns in genomics, argued that there is an over-emphasis on profit in commercial genomics, which they framed as a substantial and pressing ethical concern. One CEO from a high-profile genetic testing company, stressed:

The vast majority of intellectual property in the biopharma diagnostics and life-science sector of industry in this country ... is developed in academic labs ... funded by the taxpayer, and...I find it a bit egregious...that upon an industry effort to kind of get it up and running ... spending most of the time selling and marketing to doctors, then sells it back to that individual at a 90 percent markup. To me, that is not ethical business practice. (Participant 30)

This CEO highlighted a widespread bioscience business practice as unethical: taking research funded by taxpayers, spending money marketing the innovation, and then selling it back to individuals with massive margins. He went on to argue that these margins far outsize those in other industries (as much as 9:1, he says), and he argued that the US Congress simply doesn't seem to understand this. Ultimately his mindset let him to suggest that it isn't regulation, but competition that should and will solve this issue. He stressed that his company has used a focus on ethical pricing as a tool in positioning themselves both in the eyes of customers as well as personnel – competing against other companies in attracting talented employees based on the idea of their company as an ethical, mission-driven one. As part of this corporate culture, they included patient and *long-term* investor interests as priorities in the company's legal registration statement – against urgings of their lawyers, the CEO noted.

Another senior leader in a clinical genetic testing company described his concern about the profit motive:

you can think of it as...an extraction mindset, where...you have something useful that people need. You build a wall around it that's as tall as you can possibly build it, and then you extract as much value from the marketplace as you can, right? So you basically optimize for like the highest price point...that the market will bear. And that– in the business of health care....I think it's ethically problematic. (Participant 28)

This informatics specialist linked high prices with “locking up” data, arguing that some companies hide their data away and charge the highest prices possible for their services, which he suggests is “ethically problematic” when people’s health is on the line.

Other interviewees denigrated people or companies who are focused primarily on profit, as opposed to human health and wellbeing, or science more broadly. The former CEO of one “unicorn” genomics company (having a valuation over \$1 billion) contrasted the Bay Area biotech world “that really pushed back the frontiers of science” with other areas of the country where hubs grew up based on people who “were in it for a fast buck” (Participant 3). But while many interviewees were critical about how profit motives shape the industry, most of them ultimately placed responsibility for ethical pricing on individual companies making fair decisions. Only three interviewees argued explicitly in favor of regulatory approaches to control pricing.

Discussion

In this study, members of the US private sector genomics industry referenced a wide range of issues as pressing ethical concerns in commercial genomics, from apprehension that parties might be able to identify people based on supposedly anonymized genetic information to concerns about insufficient counseling on genetic testing services (especially those involving public sharing of genetic information in ancestry databases). Among interviewees’ concerns, major themes emerged focusing on diversity in genetic datasets, control of genetic data, and emphasis on profit – discussed further below in relation to existing ethics scholarship. Two key framing devices underlie the ways participants communicated about ethics – framing ethics as a point of competition, and framing major ethical issues as remote from one’s own work – also discussed further here below.

The concerns participants in this study expressed are closely related to discussions in academic bioscience and ethics publications, conferences, workshops, etc. This should be unsurprising, as academic and industry worlds and spaces overlap heavily, with many people straddling and moving between the two – professors who found companies, graduate students who move into industry jobs, etc (Powers and McDougall 2005, Sansone et al. 2021). These spaces overlap ever-more strongly of late, especially through university efforts toward technology transfer and entrepreneurship; Stanford University alone has set to invest over \$150 million in their startup incubator over a

five year period (Scott, Borgelt, and Lee 2014, Robinson 2019). And while industry-academic relationships have created concerns about conflicts of interest for both bioscientists and ethicists (de Vries and Bosk 2004, MacDonald 2005, Brody et al. 2007), this nexus also creates space for advancement on justice issues through robust interdisciplinary debate and reforming cultural norms, including a role for ethicists to influence the landscape of thought and practice, as discussed below.

Diversity: Race versus ancestry

Interviewees expressed great concern that historical and current trends in sampling mean that genetic datasets dramatically overrepresent people of European ancestry vis-à-vis the global population. However, interviewees diverged substantially in whether they thought of this as a question of *race* or of *ancestry*. A voluminous literature by both natural and social scientists has demonstrated that human variation is continuous, and there are not distinct breaking points on which one can lump people biologically into racial categories in any objective fashion, certainly by continent, which has generally been the basis for today’s understandings of race; in fact, there is no greater genetic similarity between Eastern and Western Europeans than between populations of Europe and Africa (Feldman and Lewontin 2008, Cooper, Kaufman, and Ward 2003, Yudell et al. 2016). Furthermore, scholars have shown that race is a poor proxy for the ancestral and genetic diversity that matters for developing research and care that works for people across populations, especially since race can actually hide biologically significant ancestry (Richard Lewontin has pointed to the example of sickle-cell in a self-identified white American who has one African great grandparent) and can promote racism in medicine by perpetuating ideas about inherent biological racial difference (Feldman and Lewontin 2008, Lee et al. 2008, Owens and Walker 2020). However, prominent journals continue to publish calls for the use of race in medicine, giving insufficient weight to the risks of using such proxies. Until this changes, it will be difficult to shift understandings of the biological basis of race in both academic and private sector biomedicine.

In the interview sample of the current study, individuals with doctoral level training were markedly more likely to focus on ancestry as opposed to race when speaking about diversity in genetic datasets. However, multiple individuals in high-ranking genomics positions in the private sector stated clearly that they believe race is discernable in genetics. This

perspective reflects an ongoing debate across disciplines and individual as well as professional positioning. Past research has shown that genetics professionals often slip between using categories of race and ancestry in various contexts of clinical and research practice (Nelson et al. 2018). But if/when those responsible for designing, developing, and marketing the next generation of genetic technologies approach race as a genetic category, it presents a major risk that these products will perpetuate inequality in health by treating people as intrinsically biologically different by race (Blell and Hunter 2019, Vyas, Eisenstein, and Jones 2020), rather than seeking the true underlying biological and social variables. While the category of ancestry (versus race) helps better attend to the biological variations that shape outcomes, the concept of genetic ancestry has itself often been inappropriately applied – based on faulty (and sometimes racially biased) assumptions about patterns of human migration that envision populations, especially on the African continent, to be largely immobile through time (Blell and Hunter 2019). Attention to ancestry must also be done with nuance, not simply as a “stand-in” for race, based on the same continental categories and associated stereotypes.

Regardless of the categories they used, interviewees consistently linked diversity in data sets with health equity. While national attention to health disparities during the Covid-19 pandemic may have shaped the ways that interviewees talked about equity, no difference is systematically apparent in the interviews conducted prior to versus during the pandemic.

Diversity: Something missing

While interviewees consistently expressed concern about diversity in genetic datasets, few in this study's sample expressed any concern about diversity within the genomics industry labor force as a whole or in the private sector specifically. This is in spite of reports highlighting the dismal numbers of Black and Latino employees in the biotech industry, especially in positions of management and senior leadership (Huggett 2018). Social science scholarship has consistently demonstrated that the backgrounds and mindsets of the people designing and developing technologies impact the kinds of innovation produced, and there is strong evidence that innovation work involving members of marginalized groups is more often attuned to addressing inequality (Takeshita 2012, Bucciarelli 1996, Hoppe et al. 2019, Parthasarathy 2020). But while members of the US private sector genomics industry in this study often cited health

equity as a primary consideration driving the need for diversity in genetic data sets, this did not transfer (for most interviewees) into a concern regarding the demographics of their workplace.

The interviewees in this study are primarily leadership in their companies, and influential voices in the industry. This preliminary data suggests that the issue of diversity in genetic datasets (and attendant health equity concerns) have not been fully connected in this space with issues of diversity in the workforce. This is a missed opportunity, as these equity concerns are closely linked, both in terms of their drivers (i.e., histories of structural racism) as well as the possibilities for change (diverse workforces – although not a panacea – can help build more equitable solutions, as discussed above). Social scientists have argued that biomedical researchers, technologists, and others involved in health innovation need to be better trained in equity, racism, and social justice (Hardeman et al. 2020, Owens and Walker 2020, Benjamin 2019); such training would help highlight the deeper connections between diversity in datasets and in the industry, providing foundations for and impetus toward greater equity. Further research into perspectives on diversity in genetics datasets and in the industry workforce is warranted, to better map the current thought landscape and possibilities for advancement.

Genomic data control

Like diversity in genetic datasets, interviewees' concerns about control over genetic information echo robust discussions in bioscience and ethics publications, conferences, workshops, etc. This includes interviewees' concerns regarding insufficient data sharing and research access (Fortun 2008, Villanueva et al. 2019, Knoppers and Joly 2018), that companies are selling users' data without real user understanding of that process (Raz et al. 2020, Moneer et al. 2021, Hogarth 2017), as well as interviewees' arguments that individuals must be able to control how their data are used – including control over the kinds of studies for which their data are used, with whom their data are shared, and the ability to withdraw their data if so desired (Powers 2002, Gostin 1995, Shabani and Borry 2015). Well-publicized stories of genomic data being used for studies that run counter to the interests of participants, such as the Havasupai case, have brought widespread attention to the importance of data control in genomics (Garrison 2013, Mello and Wolf 2010). Concerns over data control are, of course, not unique to genomics, and regulations protecting individuals' rights to control uses of

their data – from bank records to internet browsing histories – have expanded globally in recent years, for example with the European Union's General Data Protection Regulation (Graef, Husovec, and Purtova 2018, Belli, Schwartz, and Louzada 2017). Nonetheless, there are important specificities in data control in genomics, arising from the ways genomes combine both physical and informational elements and connections to the self and others – elements that contribute to the sensitive nature of genomic data, and discussions of control over its use (Sulmasy 2015, Smith and Miller 2021).

Both interviewees and scholars have thus emphasized the importance of balancing imperatives for genomic data sharing with individual control over our genetic data. But scholars have also pointed out that an over-reliance on individual choice can serve to bypass or undermine more systematic protections, leaving the responsibility for social protection at the hands of individuals (often in a relationship of consumption, in buying services like genetic tests), when more robust societal-level decisions and protections are needed (Williams 2012, Clayton et al. 2019, Prince 2013, Taylor 2012). A small number of interviewees advanced versions of this argument, such as the CEO cited above stressing the need for “guardrails on what the data can be used for” beyond simple consumer choice, for example disallowing incest or sexuality research as her company does, especially when participants think their data is being used for to improve peoples' health.

Pricing and profit

Interviewees' comments and concerns about pricing and profit in genomics sit within a field of conflicting narratives on North American biomedicine. While there is evidence of some waning in the unbridled enthusiasm for privatization in health research and practice that was so central to American policy and public discourse at the end of the twentieth century (Best 2014, Kotsko 2020), American universities and government agencies continue to lobby for a strong role of the private sector in biomedical innovation (Scott, Borgelt, and Lee 2014, Robinson 2019). But scholars have demonstrated how privatization can undermine equity and justice, as public health programs continue to be eroded in favor of expensive, cutting-edge consumer technologies and as private sector actors control large amounts of biomedical data and other resources (Spector-Bagdady 2016, Parham, Michie, and Allyse 2017, Wilbanks and Topol 2016).

And while a substantial proportion of biomedical researchers, healthcare practitioners, and the general public express concern about the influence of industry in healthcare and biomedical research (Mecca et al. 2015, Lesko, Scott, and Stossel 2012), debate on the topic has become rather polarized (Murdoch and Caulfield 2009, Brody 2011, Huddle 2011, Taylor 2013). Much of the debate has focused on the influence of profit motives (i.e., are they inherently corrupting?) and on pharmaceutical pricing (i.e., what are acceptable pricing levels when dealing with the fundamental human right to health, and outgrowths from publicly-funded research?). In the current study, members of the private sector genomics industry in the US spoke of these questions of pricing and profit as among their chief concerns in their field, often positioning themselves in opposition to negative tropes regarding profit in the private sector – e.g., the corporate stooge out for a “fast buck” rather than in this line of work to advance science and human health.

Since the emergence of the first direct to consumer genetic tests, scholars have expressed concern that companies are profiting by *selling* tests that collect extremely valuable personal genetic data – convincing people to pay to give their data away (Jordens, Kerridge, and Samuel 2009, Spector-Bagdady 2016, Hogarth 2017). This on top of concerns about the commodification of identity – selling people products rooted in narratives about genetics as the “true self” – and predatory behavior of selling products that are not sufficiently rooted in scientific evidence (Lee 2013a, Bolnick et al. 2007, Parry 2013). But while scholars have raised such concerns about DTC genomics, questions around pricing and profit from genomic technologies have, even so, received less attention in bioscience or ethics spaces than concerns about diversity in datasets or control of genetic data. This is perhaps unsurprising, as these latter two issues arise for both academic and industry spaces, whereas pricing and profit are more specific concerns focused on industry. However, the framings of profit are especially telling of the thought worlds (Dougherty 1992, Homburg and Jensen 2007, Räisänen 2010) of members of the private sector genomics industry: that is, how people who work in this space think about the ethical and social dynamics of their work, and what this might mean for the directions the industry is moving and possibilities for driving toward greater justice. In expressing concern about price and profit, as described above, some interviewees argued that competition can help address these problems; that is, they argued in favor of market

mechanisms, even as these have been shown to be drivers of the problem (Arnold 2009, Kesselheim, Avorn, and Sarpatwari 2016, Light and Lexchin 2012). Many interviewees were more critical about how capitalist logics have shaped the industry, but most described the responsibility for ethical pricing as falling on individual companies; only a small number argued in favor of government intervention to regulate pricing. And while many interviewees expressed concern about price and profit, few felt they had any power to motivate change in this area.

Ethical distancing

In this study, interviewees rarely expressed concern about issues specific to their own subsector of the genomics industry (or at least the segment where they worked at the time of the interview), nor about approaches of their own teams and companies. People working in prenatal testing, for example, did not express concern about the ways that discriminatory understandings of “healthy” and “normal” children might shape users’ reproductive choices based on the company’s tests. Nor did people working in artificial intelligence and genomics express concern about biases built into algorithms, or people working in genetic ancestry concern about understandings of identity that might be built into such tests. And as described above, interviewees were extremely concerned about diversity in genomic datasets, but did not express concern about diversity in their own companies. Interviewees often cited concern about issues in genomics most distant from the areas in which they work specifically, rather than focusing on issues at hand in their own day to day. This may be an artifact of the interview relationship, reflecting concern about drawing negative attention to the interviewee’s own workplace. Or it may reflect differences in the sorts of concerns that social scientists see (relating to identity, ideas about “the good life,” etc.) and those that the bioscientists, engineers, and business leaders in this study see.

However, some of this trend may also reflect what scholars have called “ethical distancing” – a way that people protect themselves and their own self-opinions by reframing morally contentious behavior as seated far from themselves (Kaufmann, West, and Ravenscroft 2005, Ashforth and Kreiner 1999). Kaufmann et al, for example, describe how students who have cheated on exams then rhetorically try to “loosen” the relationships between themselves and the behavior, both by blaming others and by framing cheating as outside of their normal character. Ashforth & Kreiner have

written about how people doing “dirty work” – for tobacco companies and other fields that have received some amount of social disdain – construct positive self-images by focusing on what they see as even more disconcerting industries and roles than their own. This is not to say that behavior in the genomics industry should be seen as morally suspect; indeed, being able to tackle the socially challenging aspects of this work, without stigmatizing or dismissing it as “ethically suspect,” is a key to improving justice. But the concept of ethical distancing draws attention to the importance of this very effort – of bringing ethical attention closer to the everyday ethics of our own work, where we have the power to make change, even though we may not feel empowered to do so.

People across contexts reason in ways to protect self-perceptions (Mezulis et al. 2004, Carver and Scheier 2000). But business ethicists have highlighted the importance of expanding moral imagination, for example by helping people see issues as ethical in nature, and imagining consequences beyond the immediate contexts at hand; they’ve shown that moral analysis of one’s own work can increase sentiments of moral responsibility toward others, with positive impacts on ethical decisionmaking (Opatow 1990, Werhane 1999, Moberg and Seabright 2000). This type of nuanced and at times uncomfortable thinking about our own work is challenging, but can reap real benefits for social justice, creating space for people to influence their work in the interest of equity.

Ethics as a tool of competition

As noted above, interviewees positioned their concerns about ethics in genomics amidst the field of public debates on the sale of users’ data by genomics companies, and on the role of markets and profit in biomedicine. Many interviewees framed their own work, and that of the companies they work for, in opposition to “bad actors” in this arena – those they described as unscrupulously selling people’s data, setting exploitative prices, and developing technologies in the interest of profit rather than human health and wellbeing. Several interviewees explained how their companies are positioning themselves specifically vis-à-vis ethical issues as a way to attract both customers and employees. That is, they are framing their companies’ approaches to ethics as reason to buy their products or work for them, as opposed to their competitors.

For example, the CEO of a high-profile genetic testing company, whose critiques of high prices are

cited above, emphasized a concern for pricing justice as a central tenet of their corporate culture. Legally setting forth patient and *long-term* investor interests as priorities in the company's documentation with the US Securities and Exchange Commission, as this company has done, is not a common industry practice. This focus on long-term value runs against a widespread idea that publicly traded companies have a legal responsibility to advance shareholder interests in the short-term, which some interviewees argued is holding the industry back. Indeed, critical legal scholars have demonstrated that there is no legal precedent requiring a focus on the short term, and that companies can certainly pursue decisions that might not maximize revenue and stock prices immediately (e.g., lower product prices, etc.), but which are likely to promote the long-term success of the company through positive social perception, etc. (Stout 2012, Freeman, Harrison, and Wicks 2007). Focusing on this type of "socially conscious business" is not only "the right thing to do," but helps attract talented employees, this CEO stressed. And while one might critique the transformation of ethics into a concern rooted in capitalist competition, concerns expressed by members of the genomics industry in this study do appear to have power in driving company approaches toward a justice orientation.

Further research

Members of the private sector genomics industry in this study cited a wide range of concerns in genomics today, and no single issue was spontaneously cited by an absolute majority of participants. Additional research should further investigate, describe, and quantify levels of concern amongst private sector genomics workers on the range of issues cited here – including data control, ownership and governance; profit motives; race vs ancestry; diversity in the workplace – as well as how perspectives differ amongst employees in genomics companies in countries around the world, by domain, etc. This data gives important insights into the future of the industry, and can be used to drive industry efforts on these areas of concern. This is not to say that concerns amongst members of the industry are the only ones that should shape efforts toward greater justice in this arena; as noted above, the concerns that ELSI scholars have raised about genetics and identity or group harm, for example, appear little present in the concerns of interviewees here. Nonetheless, describing levels of industry concern can provide evidence to support action.

Conclusion

In the private sector genomics world, new technologies are being developed into products and services that will guide clinical practice, research efforts, data interpretation, and consumer technology for years to come. Understanding how members of this industry think and talk about their work can provide insight into the directions the industry is moving, as well as possible futures of this space. For example, one might bemoan the reduction of concerns around the ethics of pricing and data control into tools for capitalist competition amongst companies, or means for positive self-presentation. However, the level of concern on these issues amongst members of the industry suggests that some amount of substantive change might indeed come about if more and more companies are using their ethics practices as ways to attract employees. Additional support – be it through policy, popular attention, etc. – might help drive these efforts toward justice. However, the mismatch between high levels of concern regarding diversity in datasets and much less concern about diversity in the industry itself suggests that this element of justice in technology development may not be driving the direction of the industry as much as one might have expected from the omnipresence of diversity talk. Likewise, the forms of "ethical distancing" at play in this arena and the ways that "ethics" has become associated with "boring trainings" suggest that deeper engagement between the academic ethics community and industry might help promote understandings of ethics as an area where members of genomics companies can wrestle with the challenging and significant questions of this moment in genomics – and with this, grow the moral imagination to support difficult thinking on ethics in the day to day operation of one's own work. This sort of engagement with ethics is crucial to making the genomics industry a leader and model for equity.

Note

1. In this paper, startups focusing on genomic technologies as well as pharmaceutical companies working in genomics will be referred to as "genomics companies."

Disclosure statement

No potential conflict of interest was reported by the author.

Funding

This work was supported by the National Human Genome Research Institute under Grants K99 and R00 HG010499.

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