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SCIENTIFIC CONTRIBUTION

The epistemic harms of direct-to-consumer genetic tests

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Abstract
In this paper, I provide an epistemic evaluation of the harms that result from the widespread marketing of direct-to-consumer (DTC) genetic tests. While genetic tests are a valuable accessory diagnostic tool when ordered by a medical practitioner, there are different implications when they are sold directly to consumers. I aim to show that there are both epistemic and non-epistemic harms associated with the widespread commoditization of DTC genetic tests. I argue that the epistemic harms produced by DTC genetic tests have been disregarded in discussions on the topic. Drawing on the notion of contributory epistemic injustices, I highlight two pertinent epistemic harms: (1) a failure to uptake an individual's articulations about their identity and (2) the presiding reductionist framework dismisses useful hermeneutical resources. I then propose ways to mitigate these harms.

Keywords Epistemic harms · Direct-to-consumer (DTC) genetic tests · Epistemic asymmetries · Health policy

Introduction

Sigrid E. Johnson – an adopted half-Black, half-Italian woman – took a DNA ancestry test when she was 62. To her surprise, the results showed that she only had around 2.98% African ancestry (Padawer 2018). Johnson had been confident that she was Black. She had identified as a Black person and was a member of African American communities who considered her to be Black. Following these results, she recalls being deeply unsettled. She questioned her identity. Who was she after all? A second test, taken three years later at the same company, revealed a much higher percentage of African ancestry. Around 10% DNA was from Benin/Togo, 9% from Mali, and 8% from Ivory Coast/Ghana. The company that did the test had changed its algorithm, and Johnson's results thus changed overnight.

Discrepant results are frequent in direct-to-consumer (DTC) genetic testing. One might ask "how can results be so variable given that Johnson's underlying DNA remained the same since birth?" Consumers seeking health data have experienced similar frustration over variations in their test results, specifically as it relates to risk factors (Peikoff 2013). Consumers report being classified as "below risk" by one company but at "increased risk" by a different company for the same condition (Kutz 2010).

In this paper, I show that DTC genetic tests are a source of both epistemic and non-epistemic harms.[1] While non-epistemic harms have been the object of scrutiny, epistemic harms produced by DTC genetic tests have been disregarded in discussions on the topic. This paper addresses this gap by arguing that these epistemic harms take two forms: (1) a failure to uptake an individual's articulations about their identity and (2) dismissal of alternative hermeneutical resources due to a presiding reductionist framework. I argue

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[1] In this paper I start by outlining some problems found in health-related tests and then focus on ancestry tests. This is because ancestry testing is, historically, bound with the emergence of health-related tests. It is though important to note that health tests are regulated by the FDA, while ancestry tests are not. Consequently, requirements for accuracy and risk predictions in health-related tests are subject to tighter regulatory controls than in ancestry tests. This suggests that more rigorous scrutiny of both ancestry and health tests will have an impact on their reliability and trustworthiness. Also, ancestry tests and health-related tests differ in the kind of information they provide. Health-related tests provide a risk score, while ancestry tests provide information about similarities between an individual and other samples in a reference database. The problems of bias, accuracy, and reproducibility that I will highlight in this paper apply to both kinds of tests.

that both epistemic harms arise from asymmetrical knowledge relationships between test providers and consumers. I base the discussion of epistemic harms on Fricker's notion of epistemic injustice (2007) and on Dotson's (2012) account of contributory epistemic injustice.

The paper is structured as follows. Firstly, I review the historical development of DTC genetic tests. Secondly, I discuss problems of bias, accuracy, and reproducibility in DTC genetic testing as sources on non-epistemic harms. Thirdly, I explain (1) why *trust* is paramount to epistemically just relations and (2) how *knowledge asymmetries* are the source of epistemic harms. Fourthly, I draw on Fricker's (2007) theory of epistemic injustice and Dotson's (2012) concept of contributory epistemic injustice to expound epistemic harms. The second type of harms I discuss is epistemic because it (1) challenges the status of the consumer as a knower and (2) undermines their capacities as an epistemic agent. Finally, I outline some harm mitigation strategies that can inform policymaking on DTC genetic testing and present concluding remarks.

Background

In 2003, the Human Genome Project achieved the first complete draft of the human genome. This point in the history of biology was the dawn of a new era for genetic data and information gathering. While genetic analysis is often a joint scientific endeavor involving scientists from academic and research institutions, private companies were quick to commodify genetic information.

Genotyping technologies usually share a common underlying principle: extrapolate individual genome information via comparisons to a reference database. Once DNA is extracted from human samples (e.g., saliva), repeated measurements of short sections of DNA are compared against the database that represents the reference genome (Dudley and Karczewski 2013). The goal is to detect Single Nucleotide Polymorphisms (SNPs). It is then possible to compare variations in the sample genome against information from the database. This allows scientists to make certain inferences. Percentages of similarity to a reference group indicate the likelihood of genetic variations that correlate with the onset of a disease. This technique can be used to obtain information in both health reports and ancestry reports.

An initial wave of DTC genetic tests marketed to the public focused on nutrition and health reports. In 2013, the US Food and Drug Administration (FDA) opted to regulate health reports provided by the company 23andMe (Curnutte 2017; Green and Farahany 2014; Pollack 2013). More recently, companies like 23andMe have received FDA clearance to commercialize health reports that identify genetic variants commonly associated with an increased risk of developing disease. In parallel, companies started marketing ancestry tests to provide insights about the geographic origins of one's ancestor. Ancestry tests match a person's genome to a reference database to establish which portions of the variations overlap with a percentage of the population from the same geographical origin. Ancestry tests have become an increasingly popular and lucrative product (Hogarth and Saukko 2017). By 2019, more than 26 million consumers seeking information about their genome had provided DNA samples (Regalado 2019). Because ancestry tests do not provide any health-related information, they are not currently regulated in the United States by the FDA. A mistaken ancestry test is not perceived as having the same impact as a misdiagnosis of increased risk for developing some disease. One of my goals in this paper is to show that the view that ancestry tests are innocuous is misguided, as they are a source of epistemic harms.

Matching someone's genome to an ancestral profile involves complex statistical and computational methods. Principal Component Analysis (PCA), for example, involves reducing high-dimensionality datasets to lower-dimensionality ones. Any two humans share as much as 99% of their genome. Theoretically, most mutations that are informative of disease-relatedness are then in the section where we differ. Thanks to PCA, there is no need to analyze all 3 billion base pair combinations. This would be an unfeasible task, one that would render genetic products significantly more expensive. Because companies do not analyze all 3 billion base pair combinations, they are able to market an affordable product. Costs range from $90 to $150. Without PCA, a full genome report for a single person would likely cost between $3.000 and $10.000 (Dudley and Karczewski 2013).

A few terminological clarifications are required at this stage. In the present context, ancestry is understood in terms of genetic ancestry (it relates to genomic material that indicates population origins) (Korunes and Goldberg 2021; Mathieson and Scally 2020). The concept of ancestry overlaps with concepts of race and ethnicity. In medicine, race is commonly a self-ascribed or socially-ascribed category that refers to "one's identification on the basis of physical characteristics and skin color" (Borrell et al. 2021, p. 474). Ethnicity "captures the common values, cultural norms, and behaviors of people who are linked by shared culture and language" (Borrell et al. 2021, p. 474). As such, even if DTC genetic testing companies are only providing information about genetic ancestry, the information overlaps with consumers' racial and ethnic identities.

Bias, accuracy, and reproducibility of DTC genetic tests as a source of non-epistemic harms

In 2006, the United States Government Accountability Office (GAO) produced a report indicating that there were serious problems related to accuracy and reproducibility in health-related DTC genetic tests. The report concluded that many companies were making medically unproven predictions (Kutz 2010). Using undercover consumers, the GAO obtained results from several companies for the same samples. Identical DNA submitted to different companies yielded different risk profiles. Several risk predictions also contradicted consumers' actual illnesses and family histories.

Following the GAO's report, various measures (e.g., an FDA ban on health reports) were implemented to regulate companies trading in health data. However, there was no specific product regulation for consumers looking to uncover their ancestry. Problems of accuracy therefore persisted (as shown in the case of Sigrid E. Johnson). An overview of the problems encountered in health-related tests sheds light onto problems that remain unaddressed and unregulated in ancestry tests. In this section, I discuss some of the reasons why there are such problems. In doing so, I evaluate problems of Eurocentric bias, accuracy, and reproducibility of DTC genetic tests.

Eurocentric bias in datasets

PCA methods are often used in combination with Genome Wide Association Studies (GWAS) to assess ancestry patterns (Dudley and Karczewski 2013; Ringnér 2008). GWAS are a key source of information for insights into the genetic origins of some diseases. GWAS are typically used as reference databases against which to compare risk across populations. Population admixture is the process by which sudden or gradual transfers of genetic material occur between populations that were previously isolated (Hellenthal et al. 2014; Korunes and Goldberg 2021).

PCA is less accurate for admixed DNA results. One reason for this is that reference databases and the majority of GWAS use population samples that are predominantly European (Martin et al. 2017). Most knowledge on phenotypically diverse traits is therefore based on studies that focus on European ancestry (Korunes and Goldberg 2021). Lack of database diversity means that risk estimates are more accurate for populations that are most similar to the samples they are compared against due to sampling bias. In most cases, databases are primarily composed of individuals from WEIRD societies (Westernized, educated, industrialized, rich, and democratic) (Henrich, Heine, and Norenzayan 2010). This naturally excludes ancestries that do not belong to this category. WEIRD societies are though not representative of the overall human population. This bias is likely to extend into the reference populations used by DTC genetic testing companies. Companies like 23andMe acknowledge this bias[2] and have made moves towards rectifying it by including more diverse databases. However, DTC test providers are not always open about this limitation.

Given the above, there is relatively high prediction accuracy for European populations, and this is so for both health-related risks and ancestry predictions. But, predictive accuracy decreases significantly for Hispanics/Latinos and African Americans (Henrich, Heine, and Norenzayan 2010; Kim et al. 2018). This is evident in the way that different *p*-values show higher risk allele frequencies in admixed samples than in European samples. Analytical findings on individual SNPs are often at odds with clinical data available for the African American population. This discrepancy may suggest that genetic risks are currently being misestimated for individuals with predominantly African ancestry (Kim et al. 2018).

In sum, legitimate questions around predictive accuracy arise when considering results for non-European individuals given that the reference genome is a biased sample.

Accuracy and reproducibility

Sampling bias leads to a significant problem for admixed samples. This is that systematically less accurate results are obtained. As the GAO report shows, results also suffer from a reproducibility problem. Accuracy and reproducibility are often characterized as values in science (Douglas 2009). Accuracy captures how close a measurement is to the actual value of what is being measured. There are cases where the attribute being measured changes over time (e.g., behavior or well-being). However, in the case of DNA information, the underlying attribute – the sequence of base pairs in a DNA sample – remains the same. We therefore *expect* that information provided about our DNA will be reliable. Despite this, there are notable problems with the reproducibility of results. Different companies may use different techniques for measuring the same sample (a person's DNA). Also, data processing methods may be updated over time, and consumers may find sudden changes in their reports given that the information provided is usually a prediction or an estimate.

When interpreting results that represent admixed populations (e.g., for a Mexican-American person or someone with

[2] An example can be found on this page from 23andMe's website: https://www.23andme.com/en-ca/ancestry-composition-guide/#:~:text=Your%20Ancestry%20Composition%20report%20shows,14%2C000%20people%20with%20known%20ancestry.

both African and European ancestry), PCA encounters an extra level of complexity. This is due to the fact that admixed samples have DNA coming from different geographical locations (Kidd et al. 2012; Kim et al. 2018). A lack of diversity in most databases leads to systematically less accurate results for individuals with admixed DNA. A study by Kim and colleagues' (2018) shows that most disease-associated loci were discovered in non-African populations. As such, "alleles segregate at intermediate frequencies in non-African populations but are found at extremely low or high frequencies in Africa" (Kim et al. 2018, p. 4). Contrary to null expectations, GWAS using African cohorts show that risk allele frequencies are similar across all five continental populations.

Accuracy poses an additional problem in the case of ancestry tests. DTC test providers rely on a dubious premise: that geographical locations correspond to genetic ancestry at a high level of resolution. Currently, discussions are taking place about whether genetic ancestry, based on geographical origin of samples, is a good proxy to make predictions. For example, a report issued by the National Academy of Sciences (Committee on the Use of Race, Ethnicity, and Ancestry as Population Descriptors in Genomics Research 2023) highlights the different ways in which scientists measure genetic ancestry across studies, showing high variability in those measures as well as raising legitimate questions about the use of genetic ancestry as a reliable category to cluster samples.

The problems of bias, accuracy, and reproducibility outlined in this section constitute a set of non-epistemic harms that consumers can face. Non-epistemic harms have been scrutinized in the literature (e.g., Duster 2011; Bandelt et al. 2008). I will therefore only provide an overview, one that provides the basis for the argument I am advancing in this paper. Namely, that epistemic harms have been disregarded in discussions on the topic and should be the object of consideration.

Overview non-epistemic harms

A first non-epistemic harm involves the violation of a contractual obligation to deliver reliable information. As in Sigrid E. Johnson's experience with ancestry tests, misleading information and discrepant results can be psychologically distressing. For example, Johnson recalls a feeling of embarrassment, disorientation, and a fear that others might think of her as a fraud.

A second non-epistemic harm results from the fact that providers often downplay the probabilistic nature of data and instead use deterministic language to market their DTC tests. Also, unnecessary use of DTC genetic tests can create more demand for superfluous health check-ups. This can, in turn, put pressure on health resources that could be directed towards patients with more legitimate healthcare needs, resulting in an unfair distribution of resources (Williams-Jones and Burgess 2004).

A third non-epistemic harm relates to unnecessary (and potentially negative) changes in lifestyle, changes that are prompted by certain test results. A person whose test results indicate that they have an increased risk of coronary disease is likely to change their lifestyle in a positive way; they might make healthier choices. Some might say that such changes are desirable, even if the person is not at high risk. However, there is a problem when false negative results are obtained. Consider a consumer who has been told that their risk of developing heart disease is below average. They might make poor diet and lifestyle choices based on such results (which recall are only probabilistic). Misleading information has practical consequences for how people make decisions about how to lead their lives, that is, it negatively affects their autonomy.

Some might argue that, once problems of bias, accuracy, and reproducibility in DTC genetic tests are resolved, such tests will become ethically innocuous; they will no longer constitute a source of harm to consumers.

Some might also object that testing and validation generally yield very high precision (e.g., predicting whether a piece of DNA that belongs to a given population *actually* comes from that population). An objector might also point out that testing and validation generally yield high recall percentages (e.g. predicting how often fragments of DNA from a given population *are* from that population) (23andMe 2022). Accordingly, it may be argued that insofar as companies strive to improve these percentages, there might be no real underlying harm suffered by consumers.

In response to these objections, I contend that there is a more concealed type of harm embedded in these tests. This type of harm is intrinsically epistemic, and it stems from asymmetrical knowledge dynamics between consumers and providers. As part of my argument in the next section, I will show that, even if problems of bias, accuracy, and reproducibility are eliminated, some important epistemic harms will remain.

If (as I assume) consumers of DTC genetic tests *seek knowledge* about their genetic composition, then, *qua* knowledge seekers, they are *epistemic* agents. Thus, the harms I am concerned with are epistemic; they challenge the status of the consumer as a knower; they undermine the consumer's capacities as an epistemic agent.[3] My discussion of

[3] While such harms are epistemic, it is also possible to interpret them as a threat to autonomy. Test results and deceitful rhetoric can alter one's capacity to be one's own person, that is, to independently pursue goals that are not distorted or manipulated by external factors. Here, I am concerned with how such threats to autonomy also threaten

epistemic harms will be grounded in the question of epistemic trust (or the lack thereof).

Trustworthiness and asymmetries between fields of expertise and laypersons

Relations of trust between experts and laypersons have been extensively discussed in philosophy of science and social epistemology (Baier 1994; Grasswick 2010; Hardwig 1991; Hawley 2017; Hendriks, Kienhues, and Bromme 2016; Leefmann and Lesle 2020; McCraw 2015; Wilholt 2013). Broadly, philosophical accounts of trust rely on two expectations: (1) how another person will behave and (2) how they ought to behave (Segers and Mertes 2022).

An important epistemic harm stems from how knowers place their trust in knowledge providers, a relation known as epistemic trust. Epistemic trust relates to the reliance that knowers place in knowledge providers. However, trust goes beyond reliance. It implies that the knowledge provider is trustworthy in virtue of their status as an expert in some field, that is, that the knowledge provider shares a sense of what the "right attitude towards the aims of a collective enterprise is" (Wilholt 2013, p. 251).

Trust can play an ambiguous role. While it can highlight knowledge asymmetries between experts and laypersons, it can also be a source of empowerment. Advances in medical technologies and devices, for example, mean that patients no longer rely solely on an expert's authority. Increasingly, patients can participate in obtaining and processing information about themselves (Segers and Mertes 2022). However, access to information that is mediated by technological advances only empowers users insofar as they understand the information being provided. Also, both providers and the information itself must be trustworthy. The consumer's well-being may not be prioritized when this situation is complicated by many stakeholder interests. As Seppe Segers and Heidi Mertes argue,

> involvement of various stakeholders in this complex network – including governments and corporate actors with economic interests – may be a reason to be critical about the motivations with which these parties promote the adoption of these technologies (2022, p. 83).

In the case of DTC genetic tests, use of reductionist rhetoric (i.e., reduction of complex constructs such as identity and ethnicity to genetic information) by test providers points to a trade-off between (a) increasing product sales by upselling the relationship between ancestry and identity, thus inflating the information the product delivers and (b) providing reliable and trustworthy information about ancestry.

Grasswick (2018) distinguishes between responsibly and irresponsibly placed trust. In an ideal scenario, there will be a balance between the degree of trust an agent places in a source and the trustworthiness of that source. However, we sometimes irresponsibly place trust in a source while ignoring that source's degree of trustworthiness. These are cases where we trust some source despite lacking good reasons for doing so. Generally, this results from a lack of means for assessing the source's trustworthiness. Irresponsibly placed trust occurs when we are not able to identify or properly consider the reasons why we should not trust a source. What is important for my purposes is that irresponsibly placed trust can be epistemically harmful to the trust-placer (to the epistemic agent).

Epistemic trust is foundational to our scientific knowledge-sharing practices (McCraw 2015; Grasswick 2017; Hardwig 1991; McCraw 2015). It is therefore key to epistemic relations between scientists and laypersons. I assume that most consumers of DTC tests are laypersons (i.e., consumers without expertise in genetics but who are curious about their genome). For trust to be possible, a layperson trusts the information provided by an expert because the expert is believed to be trustworthy and to provide reliable information. When they receive their test results, consumers are in a position of relative ignorance regarding the knowledge the expert possesses.

A successful trust relation must fulfill two basic conditions: *competence* and *sincerity* (Hardwig 1991; Grasswick 2018). Competence means that the knowledge-holder has the necessary skills to produce knowledge in a specific domain. Sincerity means that the one who is trusted will accurately convey results to the trust-placer and express their knowledge in a truthful way.

Accounts of institutional trust are sometimes modeled on accounts of personal trust. However, as Grasswick claims, trust in institutions also depends on the "trustworthiness of the specific practices of the institution" (2018, p. 77). She suggests that criteria of competence and sincerity in personal relations be expanded by adding certain specifications, specifications that apply to trust in both institutions and groups of experts.

For Gasswick, the competence condition must be reframed as a condition of competently conveying significant knowledge. In the case of science, this would mean that we trust scientists to be engaging in "epistemically valuable work" (Gasswick 2018, p. 78).

The sincerity condition is only sufficient when accompanied by a 'care' clause. Grasswick (2018) calls this "the

the consumer's position as a knowledge-seeker (assuming that most consumers are curious about their genetic history). This is why I am focusing on epistemic harms (even if they can overlap with threats to autonomy).

sincerity/care condition"; sincerity captures a minimal condition of care. To sincerely convey knowledge, Grasswick argues, knowledge-holders (experts) must *care* for knowledge-receivers (laypersons). A doctor must care for her patient to sincerely convey a difficult diagnosis rather than because she feels pressured to provide a conclusive diagnosis. This relationship is premised on the fiduciary duty that clinicians have to their patients. Doctors are required to act in the best interests of their patients.

When someone places their trust in an expert, they are entering into an inherently asymmetric relationship. The connection between trust and *vulnerability* then becomes salient (Baier 1994). Laypersons are in a vulnerable position when they rely on experts to deliver accurate and reliable information. Consider a doctor who gives a patient information about their health or a scientist who shares a groundbreaking discovery with the public. In both cases, an expert holds specialized knowledge. This would appear to justify placing one's trust in them. But, laypersons may not have all the resources to assess the validity of expert claims. It is generally accepted that, although a scientist's job may not be to uncover *the truth*, they are committed to making true claims about the subject matters they study. Likewise, a doctor is responsible for giving patients truthful information about their conditions and for offering suitable treatment alternatives that match the true state of the patient's health.

Some may argue that DTC genetic testing companies are not bound by the same fiduciary duty to consumers. After all, private companies are first and foremost obligated to stakeholders. Regulations should only apply to cases of false or deceptive advertising. On such a view, the professional obligations of experts like clinicians do not transfer to companies selling non-medical devices (e.g., ancestry tests). My response is that DTC genetic testing companies have a responsibility to consumers. These companies are delivering information about consumer's biological constituents (their genomes). This epistemic relationship involves a stronger commitment than one involved in a company selling a regular non-genetic-related commercial product to consumers. This is mainly because the product itself (allegedly) delivers information *about* a person's own genetic material. There are two reasons why I contend that companies must take responsibility for delivering reliable information to consumers.

Firstly, the product in question involves processing biological material, material that holds important information about a person. Accordingly, the information delivered may change a patient's lifestyle. It may also change their self-perceptions and their understanding of their identity. This can naturally lead to distress (as in the case of Sigrid E. Johnson). Thus, while companies might not be bound by a fiduciary duty, they are responsible for delivering reliable information to consumers, appropriate guidance, and interpretive tools that adequately inform consumers about the accuracy and limitations of the information received.

Secondly, as providers of genetic information, DTC testing companies are seen as a source of *authority* on the matter. This is an authority over people's own DNA information. The information is not innocuous in the same way that non-medical products are. The fact that DTC testing companies are processing information about a person's biological constitution is accompanied by an obligation to provide trustworthy information. This is why trust should be central to DTC testing companies' business practices even if they are primarily obligated to stakeholders. This might render the selling of DTC genetic tests less ethically problematic.

The competency and sincerity conditions for trust are not adequately fulfilled in relations between consumers and DTC genetic testing companies. This is for three reasons.

Firstly, the sincerity condition is only partially fulfilled. There are significant problems of bias, accuracy, and reproducibility in the data processing techniques employed in DTC genetic testing. Experts possess the knowledge to process and deliver the information. Yet, company representatives often do not competently address the inferential limitations of data processing techniques. Take Sigrid E. Johnson's case again. She was unable to obtain satisfactory explanations for her results from the test providers, and this caused her significant distress. The depth of information that providers make available varies greatly. Only some companies are (at least, relatively) transparent about the limitations of their methods and results.

Secondly, concerning the care condition, even when test providers aim to sincerely deliver results, it is unclear whether they do so out of care for consumers. Providers wish to sell as many tests as possible and to build a genetic database that can lead to further financial gains. Consider the following example of personal trust. Suppose a physician suspects that a patient has a higher risk for developing some disease, a disease that is normally associated with a certain ethnicity. The physician asks her patient to take a genetic test to find out whether they have a certain ancestry. This is because the physician would like to *care* better for her patient through delivering reliable information. If the physician requests a genetic ancestry test, it is safe to assume that she will deliver the results sincerely because of the care she has for her patient. In the case of DTC genetic tests, consumers rely on the sincerity of the testing company without the care component that can secure trust in knowledge-holders.[4] It is within reason to question whether the care relation is fulfilled to a degree that would match the epistemic trust relation between a physician and her patient.

[4] The consumer may then be unwittingly irresponsible for placing their trust in the knowledge provider.

Thirdly, as outlined previously, there are currently technical limitations to DTC genetic testing which are particularly relevant in the case of ancestry tests, which heavily rely on measures of 'genetic ancestry'[5]. It is then an overreach to claim that tests can (in principle) deliver the sort of ancestry information that they purport to (even if the accuracy of their tests improved). While DTC genetic tests can be useful for finding relatives, it is unclear how they can provide reliable information about ancestry, given the complexity of the construct and how it is assessed differently across studies and scientific communities.

An account of the epistemic harms

In the previous section, I discussed how trust is fundamental to asymmetrical epistemic relations between experts and laypersons. I also argued that conditions of trust are not met between experts in the field of DTC genetic testing (aggregated in DTC companies) and laypersons. The final step in my argument will involve demonstrating how a lack of trustworthiness results in epistemic harms.

To narrow the analysis, I will focus on the question of ancestry. This is for two reasons. Firstly, while health-related tests may be a source of epistemic harm, they do not necessarily provide information that overlaps with a person's sense of identity (in the same way that ancestry tests allegedly do). This is however the case with ancestry tests. Secondly, there is evidence for increasing regulation of health-related tests by government agencies such as the Food and Drug Administration (Curnutte 2017; FDA 2020). This may dissolve some of the harms emerging from health-related tests in the long term. Unlike health-related tests, ancestry tests are perceived as innocuous and marketed more broadly.

Fricker (2007) argues that there are two kinds of epistemic injustices: *testimonial injustices* and *hermeneutical injustices*. Both kinds of injustices are grounded on identity prejudice, i.e., when a member of a group is subject to a negative stereotype wrongly attributed to the group. Testimonial injustices occur when a speaker is given less credibility in virtue of having a particular social identity (e.g., woman, Black, poor, and so on). Hermeneutical injustices occur when "a gap in collective interpretative resources puts someone at an unfair disadvantage" (Fricker 2007, 1).

Moreover, a harm can be incidental (or accidental), as opposed to systematic, if it results from a one-off case of credibility deficit. An incidental harm, for Fricker, does not count as a case of epistemic injustice, but rather as a case of epistemic bad luck. By contrast, the same harm would count as systematic if the person is excluded from knowledge practices because they belong to a prejudiced identity group. With incidental harm (epistemic bad luck), the prejudice in question does not render the subject vulnerable to other kinds of injustice (e.g., legal, economic, or political injustices). With systematic harm, the person is subject to other kinds of injustice that track their social identity, thus resulting in epistemic injustice.

In response, Dotson (2012) argues that the distinction between epistemic injustice and cases of epistemic bad luck is not as clear-cut as Fricker supposes. There are cases where epistemic bad luck can constitute an epistemic injustice. Dotson's view is especially informative for the topic I am concerned with.

Dotson introduces a third kind of epistemic injustice (to go along with testimonial injustices and hermeneutical injustices). She calls this *contributory injustice*. A contributory injustice is an injustice that falls in the gray zone between epistemic injustice (systematic harm) and epistemic bad luck (incidental or accidental harm). A contributory injustice is defined as a circumstance where

> an epistemic agent's willful hermeneutical ignorance in maintaining and utilizing structurally prejudiced hermeneutical resources thwarts a knower's ability to contribute to shared epistemic resources within a given epistemic community by compromising her epistemic agency (Dotson 2012, p. 32).

In other words, Dotson's notion of contributory injustice captures cases where both parties in an epistemic relationship have appropriate hermeneutical resources, but there is still a willful exclusion of some resources to privilege others belonging to dominant views. Miller Tate (2019) explains, "contributory injustice picks out cases where relevant resources have been developed and used by the marginalized group, but not taken up by the dominant group". (p. 97)

The notion of contributory injustice can help explicate two epistemic harms that emerge from the widespread use of DTC genetic tests. As I will show, the two harms I discuss below partially align with Fricker's two kinds of epistemic injustice. But, they are better captured by Dotson's notion of contributory injustice. As we will see, this is so for two reasons. Firstly, contributory injustice captures harms located in a gray area between systematic epistemic harms and epistemic bad luck. Secondly, contributory injustice captures cases where there are hermeneutical resources available but a failure to employ these resources leads to epistemic harm.

[5] The imprecision of 'genetic ancestry' as a scientific concept has recently been discussed in a report on the use of population descriptors produced by the Committee on the Use of Race, Ethnicity and Ancestry as Population Descriptors in Genomics Research, organized by the National Academy of Sciences (2023).

Epistemic harm 1: failure to uptake an epistemic agent's articulations about their identity

Most consumers seeking to purchase a genetic ancestry test wish to understand their identity better by looking for answers to questions like "who am I?" and "where did my ancestors come from?"[6] These questions represent a common yearning to make sense of one's place in the world. DTC genetic testing companies are aware of this yearning.[7] While determinants of identity go far beyond genetic composition, DTC genetic testing companies upsell a strong connection between genetics and identity. As mentioned, DTC genetic testing companies are in a position of authority when results are delivered by experts who ostensibly possess the requisite knowledge, tools, and techniques to process genetic information. This is the case regardless of the trustworthiness of the information provided. In contrast, consumers are in a position of relative ignorance or dependence (viz. vulnerability) regarding how information is extracted from their DNA.

Most consumers already have some articulations about their identity. They are though often looking to enhance these articulations by obtaining additional information extracted from their DNA. Since most consumers are laypersons, they often cannot adequately interpret the results and identify the limitations of DTC genetic tests. This is delegated to an authoritative source of knowledge and expertise, thereby creating the asymmetries discussed above. However, these asymmetries only lead to harm under the assumption that consumers have no resources for interpreting results. This may not always be the case. There are resources available to consumers wishing to deepen their understanding of their results. Examples include information on companies' websites, access to scientific papers and in some countries, access to genetic counselling is required to take genetic tests. If and when they are used correctly, these resources can be empowering.

Adopting Dotson's notion of contributory epistemic injustice, I contend that an epistemic problem emerges in either case (the presence of resources or the lack of resources). This problem stems from knowledge asymmetries between the parties in question. Because information is provided by an authoritative source, consumers may (a) dismiss their own articulations about their identity or (b) inadvertently replace their own articulations about their identity with a reductionist narrative. The unwarranted dismissal of one articulation over another poses a threat to one's autonomy and epistemic agency. A person's identity (which overlaps with complex dimensions of one's existence) is reduced to genetic or biological information, which may conflict with existing narratives about a person's identity based on their social and personal history. In the specific case of DTC genetic tests, consumers may buy into the idea that ancestry *is* exhausted by genetic information when the information is *presented as such* by an authoritative source. This can result from unjustified trust in test providers that obtains due to the information provider's authoritative position. A consumer is free to disregard results but will be less likely to do so when the information comes from a putative expert source of knowledge.

While race, ancestry, and ethnicity are important constituents of one's identity (Appiah 1998; Mills 2015a), they are not its sole constituting factors. Ancestry percentages are not proportional indicatives of belonging to a given racial category. Sigrid E. Johnson's case may again be helpful to illustrate this complicated relationship. One of the problems with Johnson's ancestry result tests is a mismatch between (a) the complex construct of identity involving her social and self-perceptions and (b) the reported percentage obtained in her DTC genetic tests. The test results she received purported (through various rhetorical and marketing techniques) to have the epistemic authority to deliver information that determined her identity and that superseded her lived experience. This can have harmful consequences. It can shape how someone thinks of themselves in ways that are contradictory to their existing and deep-rooted self-perceptions. Someone might always have thought of themselves as X, but test results coming from a supposed authority source say that they are Y. This can compromise someone's trust in their judgements about themselves.

This first epistemic harm partially aligns with Fricker's account of testimonial injustices. For, at least, some consumers, the harm overlaps with the systematic way in which some groups are systematically excluded from participating in knowledge practices. However, the epistemic harm in question also emerges in situations not necessarily grounded on credibility deficit due to identity prejudice, which is why Dotson's account appears more apt.

For Dotson, it is not always easy to make a clear-cut distinction between cases of epistemic injustice and cases of epistemic bad luck (i.e., between systematic and agential injustices). A consumer who is not of a social identity typically excluded from knowledge practices may also be epistemically harmed, falling in a gray area. Adopting Dotson's account, regardless of whether the dismissal of an epistemic agent's narrative is grounded in identity prejudice, the failure to consider one's articulation about their identity harm configures as a contributory (epistemic) injustice.

[6] Nordgren and Juengst (2009) show the use of 'genetic essentialism' on behalf of DTC genetic testing companies as key to understanding their appeal to consumers.

[7] In a 2016 television commercial, 23andMe marketed its tests using consumer testimonials from those seeking to understand "who they are" (23andMe 2016).

This occurs insofar as a dominant epistemic source fails to uptake an epistemic agent's claims about their own identity. Due to being in a position of authority, the source imposes a dominant (genetic reductionist) view on the agent's identity.

Epistemic harm 2: the dominant framework of reductionist rhetoric dismisses alternative hermeneutical resources

The first epistemic harm relates to the knowledge-seeker as a receiver of epistemic harm. This leads to a second contributory epistemic injustice, one that is related to available hermeneutical resources. As such, there is a collective (as opposed to individual) dimension to the second harm I will discuss in this subsection.

The second epistemic harm stems from a reductionist rhetoric that reduces complex constructs like personal identity to DNA information. Here, alternative resources are dismissed in the name of an allegiance to a dominant reductionist framework.

There are important arguments in the philosophy of race that elaborate on the complex relationships between race, ancestry, ethnicity, and identity. Charles Mills (2015b) for example, argues that the metaphysical depth of racial categories partly results from the fact that race goes beyond mere ancestry. More specifically, we fail to capture the metaphysical dimension of race when we attribute racial categories to an ancestral criterion.[8] Mills states as follows:

> People focus on ancestry because in this world ancestry and the other attributes usually go together, but separating them shows that ancestry is not really the important thing. What is important is the intersubjective/subjective criterion of what ancestry is *thought* to be (2015b, p. 59, italics in original).

TallBear (2013) argues likewise that genetic ancestry is not compatible with indigenous people's articulations of their indigeneity. They prefer to define their identities in terms of kinship relations.[9] Anyone holding a constructionist view of race would naturally object to the claim that ancestry and identity are linked in the straightforward way that DTC genetic test providers suggest in their marketing.

DTC genetic testing companies try to enforce the overlap between race, ethnicity, genetic ancestry, and identity. Their epistemically advantageous position allows then to assert (1) that race and ethnicity are reducible to (or, at least, explainable in terms of) genetic ancestry and (2) that this provides reliable and meaningful information about an individual belonging to a certain ancestry group. The problem is that such a narrative neglects other hermeneutical resources (such as interpretations that rely on personal and social histories and experiences, as well as kinship factors, such as in TallBear's example) that are available for making sense of the complex relationship between race, ethnicity, ancestry, and identity.

In virtue of their authoritative position, knowledge providers have an (unfair) advantage in structuring one's social and/or collective understanding (in this case, as experts in the field of human genomics). On Fricker's account, hermeneutical lacunas are more likely to arise in areas of our social life where the powerful have no interest in achieving a proper interpretation of such areas. The powerful may indeed "have a positive interest in sustaining extant misinterpretation" (Fricker 2007, p. 152). Upselling a direct relationship between ancestry and identity is a profitable oversimplification. Focusing on a nuanced and more detailed interpretation of results – one that provides adequate resources to consumers – will be more costly and therefore less attractive to DTC genetic testing companies.

Fricker's conception of hermeneutical injustice would align with cases where the injustice is due to hermeneutical lacunas resulting from hermeneutical marginalization. Cases where hermeneutical lacunas are incidental would count as cases of epistemic bad luck. As a result, some might object that, while there may be legitimate hermeneutical lacunas, interpretive resources for addressing knowledge gaps are often available and as such, no major harm is posed to consumers who have the means to access such resources. Examples include initiatives to promote genetic literacy as well as accessible transparency and accuracy disclaimers, as I will discuss in the next section.

Dotson's account once again appears more apt here since contributory injustices need not depend on a lack altogether of hermeneutical resources. Rather, a contributory epistemic injustice can also occur when hermeneutical resources are available to both parties, but these resources are not shared among or common to both parties. Specifically, a contributory epistemic injustice arises when a dominant party is biased in the use of one set of hermeneutical resources that is thought to be warranted on the grounds of their epistemically privileged position. As a result, the tendency to privilege one set of resources over another may compromise the epistemic agency of another when originating in a position of epistemic advantage. In other words, even if hermeneutical resources are available, they are not collectively shared.

TallBear's example of articulations of indigeneity may be enlightening. For TallBear, notions of identity based on genetic ancestry reconfigure indigeneity "in ways that – even without exploitative intent – can undermine tribal and

[8] An ancestral criterion can be understood as the classification of an individual into a group based on ancestry.

[9] Gannett (2001; 2004) discusses the dangers that can ensue from the conflation of ancestry, ethnicity, and race in genetic science.

First Nation's self-determination" (TallBear 2013, 512). In this case, there are two hermeneutical frameworks for understanding "indigeneity": a genomic articulation and an indigenous articulation. The problem is that the former dismisses the latter to assert a dominant narrative, instead of acknowledging it and engaging in participatory epistemic practices. This is particularly worrying in large-scale genomic studies, but it also permeates recreational genomics.

Dotson suggests that mitigating contributory injustices requires "fluency in differing hermeneutical resources" (Dotson 2012, 34). DTC genetic testing companies fail to appreciate genuine differences in the hermeneutical resources that are available for making sense of ethnicity and race. Instead, they instill their preferred hermeneutical framework by upselling the relationship between DNA and complex constructs like ethnicity, race, and identity.

Harm mitigation strategies

In this section, I discuss valuable tools at both the individual level and the policy level that can help mitigate the (epistemic and non-epistemic) harms discussed above. At the personal level, a focus on genetic literacy can provide resources for analyzing and interpreting results. At the policy level, successful cases of regulation (e.g., the FDA's regulation of 23andMe's Personal Genome Service) highlight the equally important need to regulate ancestry and health-related tests.

Genetic literacy

According to McCraw (2015), quality of communication is a fundamental condition for justified trust. Genetic literacy in prevention science can be defined as follows:

> [T]he degree to which appropriate prospective participants are familiar with and can apply information about the use of genetic data to make appropriate research participation decisions (Fisher and Harrington McCarthy 2013, p. 314).

To reduce the epistemic gap between consumers and providers, DTC companies should (or should be made to) promote greater genetic literacy. This could be done through direct communication about *how the science works*. A crucial insight that could be shared is the probabilistic nature of genetic data. The 2010 GAO report states that consumers who sought interpretation of or information about their results encountered insufficient support from the genetic counsellors whose role was to provide those interpretative or informational resources (MacDonald 2002; Hawkins and Ho 2012).

In Sigrid E. Johnson's case, different company representatives had different answers regarding the degree of confidence she should have in her results. There was no accountability for these discrepancies. Grasswick (2010) has made a similar point. She stresses the need for programs that increase marginalized communities' trust in science. Grasswick is concerned with *lack of* trust. In DTC genetic tests, there is though *unjustified* trust in the information delivered due to the so-believed authority of the information provider.

Much can be learned from the notion of 'cooperative epistemologies'. Cooperative epistemologies include laypersons in the scientific process and they provide more realistic expectations. Hookway (2010) suggests that participatory activities, such as open discussion and deliberation, are crucial to epistemic trust relations. Such activities should feature genetic counsellors and specialists who have no third-party interest in the company. This can foster a neutral environment for questions and information sharing.

Increased regulatory controls

Existing regulatory frameworks are usually inadequate when new technologies and the resulting products first become available (Curnutte 2017). This has certainly been the case with DTC genetic tests. In the United States, regulation that enables health reports to be issued by a non-medical provider were only implemented about ten years after 23andMe first marketed its products. The FDA has come to an agreement with 23andMe regarding which health-related tests can be sold. This is based on empirical data about accuracy and validity, but such regulations do not (yet) exist in many countries.

In Canada, ancestry and health-related DTC tests can be directly sold to the public. In 2017, the Canadian Medical Association (CMA) (2017) issued a policy report (CMA Report PD17-05) warning about the low predictability of DTC tests. The CMA also highlighted how some physicians lack the appropriate resources to (1) interpret test results and (2) provide patients with reassurance about their results. The landscape of genetic regulation has changed since 2017 (when discrimination on the basis of genetic information was prohibited, for example). There is though still no consumer protection against misleading or inaccurate results.

Transparency and sincerity in accuracy disclaimers of test results for different ethnic groups

Transparency standards are not homogenous across test providers. While some companies (like 23andMe) provide

some information about test validity, others provide little to no information to those interested in purchasing an ancestry test. In many cases, information about precision and recall, testing methodology, and database diversity is not made available in a clear and transparent way. The standard of information given on validity, precision, recall and accuracy should be homogenized across test providers, and would benefit from regulatory control.

Making levels of precision explicit for each ethnicity would constitute an easily implementable first step towards fostering relations of epistemic trust. Consumers could then make more informed decisions based on available information. Other procedures that could be relatively easily implemented include (1) a brief comparison between more and less precise reports and (2) a step-by-step explanation of how to interpret results. An example is that ancestry tests can be useful for finding relatives but may not deliver meaningful information about race and ethnicity. This kind of information should be made available before consumers purchase products so that they can exercise their epistemic agency in an informed way before the transaction takes place.

Conclusion

In this paper, I discussed the harms that can emerge from the widespread sale of recreational genetic products such as DTC genetic tests. I outlined how problems of bias, accuracy, and reproducibility can result in non-epistemic harms to those receiving test results, and how such problems also apply to ancestry tests.

I have argued that a more concealed type harm – epistemic in nature - has yet to be addressed. By then focusing specifically on ancestry tests, I situated my argument within the framework of epistemic trust between experts and laypersons. The conclusion to my argument is twofold:

1. Consumer's articulations of their own identity can be unjustifiably replaced by a dominant (and likely unwarranted) reductionist narrative when there is a failure to uptake their articulations about their identity.
2. There is often a dismissal of alternative hermeneutical resources due to a dominant reductionist framework.

From an epistemic perspective, I proposed two solutions for addressing the harms that result from the widespread marketing of DTC genetic tests: genetic literacy and systematic regulatory controls.

While DTC genetic tests are marketed as recreational products, they clearly have serious implications at both the policy level and the consumer level. Analyzing the epistemological underpinnings of consumer-provider relations might be a fruitful approach to understanding the different harms that can result from the commodification of genetic data.

Epistemic trust asymmetries can put consumers in a vulnerable position. Scrutinizing such asymmetries from a philosophical standpoint brings conceptual clarity to the harms that can ensue from interactions between experts and laypersons. While health-related tests are increasingly regulated, important epistemic problems arise for ancestry tests. Such problems contribute to epistemic injustices.

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References

23andMe, dir. 2016. "Everyone has a DNA story (TV ad)." https://www.youtube.com/watch?v=zaRvMQR87jM.

23andMe, dir. 2022. "Ancestry Composition – 23andMe Canada." 23andMe. 2022. https://www.23andme.com/en-ca/ancestry-composition-guide/.

Appiah, K., and Anthony. 1998. "Race, Culture, Identity: Misunderstood Connections." In *Color Conscious*, by Kwame Anthony Appiah and Amy Gutmann, 30–105. Princeton: Princeton University Press. https://doi.org/10.1515/9781400822096-002.

Baier, Anette C. 1994. "Trust and its vulnerabilities.". In *Moral Prejudices: essays on Ethics*, 130–151. Cambridge, Massachussetts: Harvard University Press.

Bandelt, Hans-Jürgen, Yong-Gang Yao, and Martin B. Richards, and Antonio Salas. 2008. "The Brave New Era of Human Genetic Testing". *Bioessays* 30 (11–12): 1246–1251. https://doi.org/10.1002/bies.20837.

Borrell, Luisa N., R. Jennifer, Elena Elhawary, Jonathan Fuentes-Afflick, Nirav Witonsky, H. B. Bhakta, Alan, Kirsten Wu, and Bibbins-Domingo, et al. 2021. "Race and genetic ancestry in Medicine — A Time for reckoning with racism". *New England Journal of Medicine* 384 (5): 474–480. https://doi.org/10.1056/NEJMms2029562.

Committee on the Use of Race, Ethnicity, and Ancestry as Population Descriptors in Genomics Research, Board on Health Sciences Policy, Committee on Population, Health and Medicine Division, Division of Behavioral and Social Sciences and Education, and National Academies of Sciences, Engineering, and Medicine. 2023. *Using Population Descriptors in Genetics and Genomics Research: A New Framework for an Evolving Field*. Washington, D.C.: National Academies Press. https://doi.org/10.17226/26902.

Curnutte, Margaret. 2017. "Regulatory Controls for Direct-to-consumer genetic tests: a Case Study on how the FDA exercised its Authority". *New Genetics and Society* 36 (3): 209–226. https://doi.org/10.1080/14636778.2017.1354690.

Dotson, Kristie. 2012. "A cautionary tale: on limiting Epistemic Oppression". *Frontiers: A Journal of Women Studies* 33 (1): 24–47. https://doi.org/10.5250/fronjwomestud.33.1.0024.

Douglas, Heather E. 2009. Science, Policy and the Value-Free Ideal. Pittsburgh: University of Pittsburgh Press.

Dudley, Joel T., and Konrad J. Karczewski. 2013. *Exploring Personal Genomics*. Oxford: Oxford University Press. https://doi.org/10.1093/acprof:oso/9780199644483.001.0001.

Duster, Troy. 2011. "Ancestry Testing and DNA: Uses, Limits and Caveat Emptor." In *Race And The Genetic Revolution: Science, Myth and Culture*, edited by Sheldon Krimsky and Kathleen Sloan, 16. Columbia University Press.

FDA. 2020. "FDA Authorizes, with Special Controls, Direct-to-Consumer Test That Reports Three Mutations in the BRCA Breast Cancer Genes." FDA. FDA. March 24, 2020. https://www.fda.gov/news-events/press-announcements/fda-authorizes-special-controls-direct-consumer-test-reports-three-mutations-brca-breast-cancer.

Fricker, Miranda. 2007. Epistemic Injustice: Power and the Ethics of Knowing. Oxford: Oxford University Press. https://oxford.universitypressscholarship.com/10.1093/acprof:oso/9780198237907.001.0001/acprof-9780198237907.

Fisher, Celia B., and Erika L. Harrington McCarthy. 2013. "Ethics in Prevention Science Involving Genetic Testing." *Prevention Science* 14 (3): 310–18. https://doi.org/10.1007/s11121-012-0318-x.

Food and Drug Administration. 2021. "Direct-to-consumer tests." FDA, June. https://www.fda.gov/medical-devices/in-vitro-diagnostics/direct-consumer-tests.

Gannett, Lisa. 2001. "Racism and Human Genome Diversity Research: The Ethical Limits of 'Population Thinking.'" *Philosophy of Science* 68 (3): S479–92.

Gannett, Lisa. 2004. "The Biological Reification of Race." *The British Journal for the Philosophy of Science* 55 (2): 323–45. https://doi.org/10.1093/bjps/55.2.323.

Grasswick, Heidi E. 2010. "Scientific and Lay Communities: earning Epistemic Trust through knowledge sharing". *Synthese* 177 (3): 387–409. https://doi.org/10.1007/s11229-010-9789-0.

Grasswick, Heidi. 2017. "Epistemic Injustice in Science." In *The Routledge Handbook of Epistemic Injustice*, edited by Ian James Kidd, José Medina, and Gaile Pohlhaus, 1st ed., 313–23. 1 [edition]. | New York: Routledge, 2017. |: Routledge. https://doi.org/10.4324/9781315212043-31.

Grasswick, Heidi. 2018. "Understanding Epistemic Trust Injustices and their Harms". *Royal Institute of Philosophy Supplement* 84 (November): 69–91. https://doi.org/10.1017/S1358246118000553.

Green, Robert C., and Nita A. Farahany. 2014. "Regulation: the FDA is overcautious on Consumer Genomics". *Nature* 505 (7483): 286–287. https://doi.org/10.1038/505286a.

Hardwig, John. 1991. "The role of Trust in Knowledge". *The Journal of Philosophy* 88 (12): 693–708.

Hawkins, Alice K., and Anita Ho. 2012. "Genetic counseling and the ethical issues around Direct to Consumer Genetic Testing". *Journal of Genetic Counseling* 21 (3): 367–373. https://doi.org/10.1007/s10897-012-9488-8.

Hawley, Katherine. 2017. "Trust, Distrust, and Epistemic Injustice." In *The Routledge Handbook of Epistemic Injustice*, edited by Ian James Kidd, José Medina, and Gaile Pohlhaus, 1st ed., 69–78. 1 [edition]. | New York: Routledge, 2017. |: Routledge. https://doi.org/10.4324/9781315212043-7.

Hellenthal, Garrett, George B. J. Busby, Gavin Band, James F. Wilson, Cristian Capelli, Daniel Falush, and Simon Myers. 2014. "A genetic atlas of human admixture history". *Science* 343 (6172): 747–751. https://doi.org/10.1126/science.1243518.

Hendriks, Friederike, and Dorothe Kienhues, and Rainer Bromme. 2016. "Trust in Science and the Science of Trust." In *Trust and Communication in a Digitized World: Models and Concepts of Trust Research*, edited by Bernd Blöbaum, 143–59. Progress in IS. Cham: Springer International Publishing. https://doi.org/10.1007/978-3-319-28059-2_8.

Henrich, Joseph, and Steven J. Heine, and Ara Norenzayan. 2010. "Most people are not WEIRD". *Nature* 466 (7302): 29–29. https://doi.org/10.1038/466029a.

Hogarth, Stuart, and Paula Saukko. 2017. "A market in the making: the past, Present and Future of Direct-to-Consumer Genomics". *New Genetics and Society* 36 (3): 197–208. https://doi.org/10.1080/14636778.2017.1354692.

Hookway, Christopher. 2010. "Some varieties of Epistemic Injustice: reflections on Fricker". *Episteme* 7 (2): 151–163. https://doi.org/10.3366/E1742360010000882.

Kidd, Jeffrey M., Simon Gravel, Jake Byrnes, Andres Moreno-Estrada, Shaila Musharoff, Katarzyna Bryc, and Jeremiah D. Degenhardt, et al. 2012. "Population Genetic Inference from Personal Genome Data: Impact of Ancestry and Admixture on Human Genomic Variation". The American Journal of Human Genetics 91 (4): 660–671. https://doi.org/10.1016/j.ajhg.2012.08.025.

Kim, Michelle S., P. Kane, Andrew K. Patel, Ali J. Teng, and Berens, and Joseph Lachance. 2018. "Genetic disease risks can be misestimated across global populations". *Genome Biology* 19 (1): 179. https://doi.org/10.1186/s13059-018-1561-7.

Korunes, Katharine L., and Amy Goldberg. 2021. "Human genetic admixture". *PLOS Genetics* 17 (3): e1009374. https://doi.org/10.1371/journal.pgen.1009374.

Kutz, Gregory. 2010. *"Direct-to-consumer genetic tests: misleading test results are further complicated by deceptive marketing and other questionable Practices: congressional testimony." Testimony before the Subcommittee on Oversight and Investigations*. Committee on Energy and Commerce, House of Representatives.

Leefmann, Jon, and Steffen Lesle. 2020. "Knowledge from Scientific Expert Testimony without Epistemic Trust". *Synthese* 197 (8): 3611–3641. https://doi.org/10.1007/s11229-018-01908-w.

MacDonald, Chris. 2002. "Commercialisation of genetic services: the role of genetic counsellors". *Human Reproduction & Genetic Ethics* 8 (1): 1–3. https://doi.org/10.1179/hrge.8.1.jl0184m51pt22576.

Martin, Alicia R., Christopher R. Gignoux, Raymond K. Walters, Genevieve L. Wojcik, Benjamin M. Neale, Simon Gravel, Mark J. Daly, Carlos D. Bustamante, and Eimear E. Kenny. 2017. "Human demographic history impacts genetic risk prediction across diverse populations". *The American Journal of Human Genetics* 100 (4): 635–649. https://doi.org/10.1016/j.ajhg.2017.03.004.

Mathieson, Iain, and Aylwyn Scally. 2020. "What is ancestry?". *PLOS Genetics* 16 (3): e1008624. https://doi.org/10.1371/journal.pgen.1008624.

McCraw, Benjamin W. 2015. "The nature of Epistemic Trust". *Social Epistemology* 29 (4): 413–430. https://doi.org/10.1080/02691728.2014.971907.

Miller Tate, Alex James. 2019. "Contributory injustice in Psychiatry". *Journal of Medical Ethics* 45 (2): 97–100. https://doi.org/10.1136/medethics-2018-104761.

Mills, Charles W. 2015a. *Blackness visible: essays on Philosophy and Race*. Cornell: Cornell University Press. https://doi.org/10.7591/9781501702952.

Mills, Charles W. 2015b. "'But what are you really?' The Metaphysics of Race." Blackness visible: essays on Philosophy and Race. Cornell: Cornell University Press. https://doi.org/10.7591/9781501702952.

Nordgren, A., and E. T. Juengst. 2009. "Can Genomics tell me who I am? Essentialistic Rhetoric in Direct-to-consumer DNA testing". *New Genetics and Society* 28 (2): 157–172. https://doi.org/10.1080/14636770902901595.

Padawer, Ruth. 2018. "Sigrid Johnson Was Black. A DNA Test Said She Wasn't." *The New York Times*, November 19, 2018, sec. Magazine. https://www.nytimes.com/2018/11/19/magazine/dna-test-black-family.html.

Peikoff, Kira. 2013. "I Had My DNA Picture Taken, With Varying Results." *The New York Times*, December 30, 2013, sec. Science. https://www.nytimes.com/2013/12/31/science/i-had-my-dna-picture-taken-with-varying-results.html.

Pollack, Andrew. 2013. "F.D.A. Orders Genetic Testing Firm to Stop Selling DNA Analysis Service." *The New York Times*, November 25, 2013, sec. Business. https://www.nytimes.com/2013/11/26/business/fda-demands-a-halt-to-a-dna-test-kits-marketing.html.

Regalado, Antonio. 2019. "More than 26 Million People Have Taken an At-Home Ancestry Test." MIT Technology Review. 2019. https://www.technologyreview.com/2019/02/11/103446/more-than-26-million-people-have-taken-an-at-home-ancestry-test/.

Ringnér, Markus. 2008. "What is principal component analysis?". *Nature Biotechnology* 26 (3): 303–304. https://doi.org/10.1038/nbt0308-303.

Segers, Seppe, and Heidi Mertes. 2022. "The curious case of 'Trust' in the light of changing Doctor–Patient Relationships". *Bioethics* 36 (8): 849–857. https://doi.org/10.1111/bioe.13064.

TallBear, Kim. 2013. "Genomic articulations of Indigeneity". *Social Studies of Science* 43 (4): 509–533. https://doi.org/10.1177/0306312713483893.

Wilholt, Torsten. 2013. "Epistemic Trust in Science". *The British Journal for the Philosophy of Science* 64 (2): 233–253. https://doi.org/10.1093/bjps/axs007.

Williams-Jones, and Bryn, and Michael M Burgess. 2004. "Social Contract Theory and just decision making: Lessons from genetic testing for the BRCA mutations". *Kennedy Institute of Ethics Journal* 14 (2): 115–142. https://doi.org/10.1353/ken.2004.0026.