

The Future of Our Roots

Direct to Consumer Genetic Testing & Privacy Implications for People of Color

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EXTENDED ABSTRACT

Introduction

According to the sociologist Alondra Nelson, "...genetic analysis is being interwoven with the legacy of the twentieth-century civil rights movement."ⁱ In 2011 the direct-to-consumer genetic testing (DTCGT) company 23andMe launched a study of more than 10,000 African Americans in an effort to "better understand the connection between DNA and disease."ⁱⁱ By 2016 the company reached a milestone of 45,000 African Americans participating in 23andMe research and the company reported it received grant support from the National Institutes of Health (NIH) to "develop a new analysis pipeline that may alleviate disparities in research."ⁱⁱⁱ However, research regarding DTCGT in non-white racial minorities is limited.^{iv}

The first study of actual DTCGT customers with racial minority backgrounds found that these customers generally "seek out the product for largely the same reason as White customers" yet several significant differences were observed between subgroups related to obtaining information about disease risk and ancestry.^v For example, researchers found that African Americans reported the greatest interest in information related to ancestry but were among the least interested in seeking DTCGT to identify their personal risk for specific diseases.^{vi} This observation is significant given the potential resource that DTCGT could provide in helping the healthcare system and industry stakeholders identify and narrow health disparities impacting communities of color. Research finds that "Genetic ancestry is a predictor of several conditions, as demonstrated by the strong correlation between proportion of African ancestry and reporting of high blood pressure, type 2 diabetes..."^{vii} Addressing these disparities is critical given the extreme personal and financial costs associated with racial and ethnic health disparities. Research suggests that "eliminating health disparities for minorities would have reduced direct medical care expenditures by about \$230 billion and indirect costs associated with illness and premature death by more than \$1 trillion."^{viii}

Given the growing availability of direct-to-consumer genetic tests (DTCGTs) and an increased focus on unlocking the promises of precision medicine to address health disparities, there is a need to bring awareness to the privacy issues attached to these tests for the general population. In particular, consumers of color may not be as nuanced when it comes to the privacy implications of using DTCGTs; it is not fully understood how privacy and cultural considerations intersect or reinforce hesitations of some racial and ethnic minorities in seeking DTCGTs to understand their risks for known health disparities like diabetes and Alzheimer's disease.

This paper will explore the privacy considerations of professionals of color around the issue of DTCGTs to better understand their perceptions of risk and cost in the growing marketplace for

digital health information. Understanding these considerations and cultural insights will be critical to ensuring the DTCGT market meets the needs of this growing consumer group, potentially expanding the toolkit of public health practitioners, researchers, and industry to better understand and address racial and ethnic health disparities.

Background

Studies have shown that DTCGTs present a number of privacy concerns that are not widely known by consumers, and if they are, consumers do not fully appreciate the harms that could result from their use of these tests. Understanding these harms and perceptions are critical for bridging the gap between opportunity, improved health outcomes, and consumer satisfaction among consumers of color.

Harms

DTCGT consumers are sending their personally identifiable and sensitive genetic data to DTCGT companies under the misconception that their data will be kept secure and private. However, while most DTCGT companies are located in the United States, consumers typically are sending these tests including their genetic information overseas.^{ix} Because this information is sent to another country, there is no way to protect the privacy, security, and storage, as well as prevent the sharing of a consumer's genetic data in that country.^x And while it was previously assumed that personal data such as healthcare data could be redacted to prevent the identification of individuals, studies have revealed that it is possible to re-identify study participants from large genetic studies, even through the use of research statistics.^{xi} Most disturbing is the fact that because of the nature of this data being genetic information, any risks to the consumer's data become risks to the consumer's relatives.^{xii}

Customer perception

The use of "wrap contracts" by DTCGT companies presents yet another privacy concern associated with these tests. Studies have indicated that these types of contracts result in consumers unknowingly consenting to terms and conditions, some regarding the privacy of their genetic data and test results, by simply viewing their website or accessing their services.^{xiii} Oftentimes, DTCGT company privacy policies do not include specific information on the privacy of the consumer's genetic information.^{xiv} In addition, these contracts include provisions that grant companies the ability to unilaterally alter or change the terms of the "contract" without ever notifying the consumer.^{xv} As a result, consumers run the risk of being unaware of new terms regarding the way their genetic data is stored, sold, or secured.

However, surprisingly, DTCGT consumers believe they have received sufficient information regarding privacy implications when purchasing DTCGTs, but studies have shown that most DTCGT companies do not provide sufficient information on their websites for consumers to make informed decisions when purchasing these tests.^{xvi} Moreover, according to recent research most consumers believe that it is likely that their genetic information will be breached, but that DTCGT companies would either not disclose their personal genetic results^{xvii}, or would consult them before sharing their genetic information.^{xviii} In addition, some consumers have reported being concerned that their genetic information could negatively impact their ability to obtain health, life and/or disability insurance. A few consumers also report concern over their employer learning of their genetic testing results. But even while DTCGT consumers expressed concern

over the possible negative privacy implications, they were willing to assume the risks of providing their genetic information to these DTC companies.^{xix} Studies have concluded that one of the reasons consumers may decide to move forward with using DTCGTs knowing some of the risks is out of a sense of doing the greater good of contributing to future research and healthcare.^{xx}

However, considering the populations selected in many of the studies referenced, there is a question as to whether these results are indicative of the perceptions of all consumers, particularly professionals of color who have witnessed medical injustices within their populations. For example, a 2003 study looking at the attitudes of premedical students of color toward genetic testing and screening found that while the students, overall, had positive views of genetic testing, African American students had a “greater negative response” toward testing.^{xxi} They were increasingly concerned about the privacy of their data and discrimination. The students also expressed concerns about privacy and the potential misuse of the genetic information, which could lead to discrimination or eugenics.^{xxii}

Methodology

This qualitative research study will utilize a phenomenological design in an effort to develop a survey instrument for a future quantitative study. The study’s philosophical assumption is rooted in social constructivism where personal values are honored and negotiated through the inductive method of “interviewing, observing, and analyzing text.”^{xxiii} This approach will allow the research team to capture the lived experience and shared meaning of several research subjects. The central phenomenon of this research study is defined as intergenerational professionals of color with varied levels of exposure to DTCGT who have and have not managed to overcome personal privacy concerns that may or may not be related to suspicions of mal-intent, minimal exposure to DTCGT technology, and fear of bias. Phenomenology is the most effective qualitative research method for this study because the stories help professionals to learn about the importance of the story and interpretive nature of the storyteller.^{xxiv} Human subject protections have not been practiced or afforded to people of color, historically, giving way to the Tuskegee experiment and stolen DNA of unknowing scientific pioneers like Henrietta Lacks. We cannot solve for health disparities and the social determinants of health disparities in communities of color without big data from communities of color. The best chance we have to solve for this is through an intergenerational approach.

Results

The project team is in the process of finalizing its stakeholder interview process including the collection and analysis of interview data. This data will be coded for themes that will inform the development of our results and discussion section. The team anticipates this data to yield a better understanding of the decision-making process of educated, community-minded, professionals of color related to DTCGT, addressing a gap in research around the intersections of DTCGT, privacy, and communities of color. Furthermore, results will inform the development of a survey instrument in an effort to identify any generalizable data for further study.

ⁱ Alondra Nelson; *The Social Life of DNA: Race, Reparations, and Reconciliation After the Genome*; Beacon Press, Jan 12, 2016

ⁱⁱ "Our Roots into the Future Project." 23andMe. <https://www.23andme.com/roots/>

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