Knowledge and Attitudes about Privacy and Secondary Data Use among African-Americans Using Direct-to-Consumer Genetic Testing

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Abstract

Introduction: The rapidly expanding direct-to-consumer genetic testing (DTC GT) market is one area where narratives of underrepresented populations have not been explored extensively. This study describes African-American consumers’ personal experiences with and perceptions about DTC GT and explores similarities and differences between African-Americans and an earlier cohort of mostly European American consumers. Methods: Twenty semi-structured, qualitative interviews were held with individuals who self-identified as Black/African-American and completed DTC GT between February 2017 and February 2020. Interviews were transcribed and consensus-coded, using inductive content analysis. Results: Participants generally had positive regard for DTC GT. When considering secondary uses of their results or samples, most participants were aware this was a possibility but had little concrete knowledge about company practices. When prompted about potential uses, participants were generally comfortable with research uses but had mixed outlooks on other nonresearch uses such as law enforcement, cloning, and product development. Most participants expressed that consent should be required for any secondary use, with the option to opt out. The most common suggestion for companies was to improve transparency. Compared to European American participants, African-American participants expressed more trust in DTC GT companies compared to healthcare providers, more concerns about law enforcement uses of data, and a stronger expression of community considerations. Discussion/Conclusion: This study found that African-American consumers of DTC GT had a positive outlook about genetic testing and were open to research and some nonresearch uses, provided that they were able to give informed consent. Participants in this study had little knowledge of company practices regarding secondary uses. Compared to an earlier cohort of European American participants, African-American participants expressed more concerns about medical and law enforcement communities’ use of data and more reference to community engagement.

Introduction and Background

The direct-to-consumer genetic testing market is quickly expanding, reaching an estimated 26 million consumers tested since its inception in the late 1990s, and is...
expected to reach over 100 million consumers by 2021 [1, 2]. DTC GT health and ancestry kits were one of the top sellers on Amazon’s Prime Day in 2019 [3]. The global DTC GT market is valued at $1.24 billion in 2019 and shows no signs of slowing [4, 5]. While research about the knowledge and attitudes of the general public toward genetic testing and DTC GT are reported [6–8], limited research explores consumers’ actual experiences with DTC GT, particularly among underrepresented populations.

Ethical concerns have been raised about DTC GT from the beginning. Adequacy of informed consent, clinical and personal utility, data protection of sensitive personal information, unnecessary use of health services, potential misleading advertising, possible harm including negative psychological effects, and the commercialization of genomic data have all been cited as reasons for concern [9, 10]. Other researchers found that DTC GT helps consumers raise genetic awareness, empower their health decisions, and participate in research to help others [11]. Public opinion reflects an interest in DTC GT as a means to gain insight into health and ancestry information, but alarm about privacy infringement remains [12, 13].

Another less frequently studied area of ethical concern is DTC GT company practices of secondary data uses, defined as the use of consumer data for purposes other than producing a report on consumer health and/or ancestry, such as research, marketing, and third-party sales [14]. Risks associated with usage and reidentification of genomic data include forensic investigations, civil lawsuits, immigration difficulties, health resource allocations, human rights abuses, and discrimination [15]. Furthermore, few companies are meeting guidelines to adequately inform consumers of risks and company practices [16]. DTC GT Websites have been shown to be difficult to navigate, contain difficult language, and lack adequate information about secondary data usage and its associated risks [14, 17].

Consumers’ personal experiences with DTC GT are not well documented, especially among people of color and underrepresented populations [18]. Disparities in knowledge and attitudes toward genetics and genetic testing have been demonstrated among racial and ethnic groups in the USA including differing uptake rates among DTC GT and clinical testing [19, 20]. A body of research is growing that examines African-Americans’ attitudes toward participation in genetics research and general trust toward genetics. African-American study participants expressed heightened concerns about the harmful use of genetic information and fear of discrimination compared to participants of other racial backgrounds [21]. Although less knowledge and lower access to DTC GT has been demonstrated among people of color and underrepresented populations [19], a recent study by Carroll et al. [20] showed similar uptake rates of DTC GT among different racial groups.

The present study aimed to build on research by Mladucky et al. [22] which explored consumers’ knowledge of secondary uses of DTC GT data, their understanding of the risks associated with these uses, and the extent of their concerns about privacy risks. Twenty semi-structured interviews were held, which revealed that consumers were aware of some secondary uses. Most participants felt that data used for research was acceptable, but thoughts about nonresearch purposes varied across participants. Few read the company privacy policy, and most expressed concerns about the privacy of their information. They expressed a desire for more company transparency and information on future use and potential risks before undergoing testing.

Methods

This study was reviewed and approved by the University of Utah Institutional Review Board (IRB).

Participants

Participants met the following inclusion criteria: 18 years or older, had completed DTC GT between February 2017 and February 2020, and self-identified as Black or African-American. A total of 24 individuals were interviewed, 4 as pilot participants, and 20 in the study cohort. Sample size was set at 20 to allow for meaning saturation, defined by Hennink et al. [23] as the point at which researchers fully understand issues, and when no further dimensions, nuances, or insights of issues can be found.

Participant Recruitment

Pilot participants met the same eligibility criteria as study participants in the Mladucky et al. [22] study and were recruited through a local Utah church and Reddit via subreddits designed to recruit study participants [24]. Study participants were recruited through ResearchMatch, a national health volunteer registry created by several academic institutions and supported by the US National Institutes of Health as part of the Clinical Translational Science Award program [25]. ResearchMatch has a large population of volunteers who have consented to be contacted by researchers about health studies for which they may be eligible [26]. Participants were given study information via email and asked to confirm eligibility and desire to participate. For the study cohort, emails were sent to 3,000 individuals, of whom 77 agreed to be contacted with additional information about the study. Of the 77 individuals, 43 did not respond to follow-up requests to participate, 6 were ineligible, 9 were eligible but not used in the cohort because the study was full, and the first 20 who responded and met study criteria were enrolled in the study.
Interviews

The research team adapted a semi-structured interview guide that was successfully deployed among 20 individuals in a study completed in 2019 by Mladucky et al. [22]. The guide was improved for clarity and effectiveness, piloted among four African-American participants, and deployed among an additional 20 African-American participants. The interview assessed four main areas:

1. Participant demographics: age, gender, self-identified race, relationship status, education level, employment, brand, and type of DTC GT ordered (Table 1)
2. DTC GT experience: test selection, motivation for testing, opinions, explanation of procedures, and experience with the privacy policy
3. Secondary use assessment: knowledge of secondary uses, provoked perspectives about possible secondary uses, knowledge of genetic discrimination protections, and trustworthiness of DTC GT company and healthcare systems
4. Reactions to interview: presence or absence of new perspectives and suggestions for testing companies

The full interview guide is available in the online supplementary materials (see www.karger.com/doi/10.1159/000525902 for all online suppl. material). Interviews were held between November 2019 and February 2020 and recorded via Zoom by author E.Z. [27]. Participants were read the IRB-approved consent script, had the opportunity to ask questions, and verbally agreed to participate in the study. Interviews were transcribed by Landmark Associates transcription services [28] and stored in an encrypted University of Utah cloud storage program. The average interview length was 38 min. Each study and pilot participant received a USD 50 Amazon gift card to thank them for their participation.

Data Analysis

Interview transcriptions were analyzed, using Dedoose software [29]. Parent codes were initially developed from the interview guide, with emerging sub-codes added throughout coding using inductive content analysis [30]. Each interview was coded independently by at least two coders. The first four interviews were coded by E.Z., B.B., and J.M., while the remaining 16 interviews were coded by pairs of coders (E.Z. and B.B. or E.Z. and J.M.). Disagreements about codes were discussed between the coders until consensus was reached. This coding strategy provided investigator triangulation [31]. Data analysis was completed using code presence versus code occurrence to control for redundant use by a single interviewer.

Results

DTC GT Experience

Initial Attitudes about Genetic Testing

At the beginning of the interview, participants were asked their general thoughts about DTC GT. The majority of participants expressed a positive opinion, stating that genetic testing could be informative, offer valuable knowledge about health and ancestry, and fill in lost history information for African-American individuals. Some participants expressed reservations about the accuracy of the results, and some had privacy concerns. Other perceived negatives of testing included high cost, potential to discover unexpected results, and uncertainty about secondary uses.

| Table 1. Participant demographics and experience with DTC GT |
|-------------------------------------------------------------|
| **Participants, n**                                         |
| Gender |                           |                 |
| Male   | 7                          |                 |
| Female | 13                         |                 |
| Age range |                    |
| 20–29 | 2                          |                 |
| 30–39 | 5                          |                 |
| 40–49 | 6                          |                 |
| 50–59 | 3                          |                 |
| 60–69 | 3                          |                 |
| 70–79 | 0                          |                 |
| 80–89 | 1                          |                 |
| Education |                     |
| High school | 1                      |
| Some college | 5                      |
| Associates | 3                         |
| Bachelors | 4                         |
| Masters | 6                          |
| Vocational training | 1                  |
| Times tested |                  |
| 1 | 14                         |
| 2 | 4                          |
| 3 | 1                          |
| 4 | 1                          |
| Test used |                     |
| Ancestry | 15                        |
| 23andMe | 9                          |
| MyHeritage | 2                      |
| FTDNA | 1                          |
| African Ancestry | 1                |
| MyAncestry | 1                      |

I think it’s great. As an African-American, there’s a lot of lost histories. There wasn’t as much records that they kept, photos and things. A lot of the family members had been lost due to separations during slavery and migrations and things like that... I’ve been able to close the gap a lot with the use of these tools. With [company], the attraction was also to look at some of the risks or health risks that they had at that time discovered. I started with [company] first to get a two for one, basically... I discovered that I’m 10 percent Ethiopian and 90 percent European, which I didn’t know. Yeah, things like that is what piques my interest. (Participant 3 [59-year-old male])

I just think knowledge is very important, no matter what you’re looking into. I think genetic testing has offered quite a bit of information. (Participant 12 [82-year-old female])
I think the major downside is having your DNA in the hands of a third party and not really knowing exactly what they’re doing with it and how secure it really is. (Participant 4 [35-year-old female])

Testing Motivations
When asked why they pursued testing, participants brought up learning about their health information, discovering ancestry information, and directly connecting with family members. Some also noted that African-American individuals sought information to fill history lost during slavery.

Being African-American, you don’t know where your ancestors are from. I thought it would give me some insight into what country my ancestors originated from since they were brought here as slaves, but nobody knows. (Participant 5 [63-year-old female])

Privacy Policy
The majority of participants remembered a privacy policy and reported skimming it; most interviewees did not read through it in great detail. Some participants mentioned specifics of the privacy policy, including opt in/out options. Reasons cited for not reading the privacy policy in great detail included habitual agreement to policies as a means to an end product, too lengthy, belief that the results were more important than anything that could be in the policy, or lack of major issues reported in reviews of the company. A few participants expressed feelings of guilt when reflecting on their decision not to read the policy in great detail.

There probably was a privacy policy, but I will be honest, I didn’t read it…. I should have, stuff like that it’s really serious. I know. I was just so gung-ho about wanting to know just that certain thing…. I’m sure it was on there. (Participant 8 [57-year-old female])

Unprompted ideas about privacy were also revealed throughout the interview. These included a general lack of concern about privacy because the world we live in has a lack of privacy anyway or a belief that the medical community already has their genetic information. Others firmly expressed that they were willing to give up privacy for the information or were not concerned about the privacy of their genetic information.

I didn’t necessarily read word for word, but before I was reading, researching them, I was reading positive and negative information … basically the same as having cell phones today. They can share your information with anybody, regardless of what their privacy policy is. They can pretty much use it for any way or whatever. (Participant 15 [62-year-old female])

Consultation with Healthcare Provider before Pursuing Testing
Interviewees were asked if they consulted with a healthcare provider before pursuing the DTC GT. The majority of participants did not consult with a provider, but some spoke with or attempted to speak with a provider before testing. Providers consulted ranged from a nurse to an ophthalmologist. Two providers recommended different clinical genetic testing, and one expressed negative thoughts about DTC GT.

Yeah. My primary care physician said that she didn’t think it was needed, but my gynecologist suggested that we get it done…. Then she was like, “There’s a lot of missing pieces, and genetics could probably help pinpoint and identify some of the things that are going on.” (Participant 1 [49-year-old female])

Secondary Use Assessment
Knowledge and Opinions on Secondary Uses
Over half of the participants reported beliefs that their DNA information or sample is used by the company or other parties for purposes other than providing them with their direct test results. When asked how, participants responded with examples related to their direct test results, but also for research, product development, criminal investigations, and selling.

When questioned about the acceptability of secondary use for research, participants reported that research is generally acceptable, depending on the specific type of research being pursued, with medical research being most acceptable. Many of the participants specifically mentioned that research negatively targeting a specific racial or ethnic group would not be acceptable.

I would say if it’s for medical research, then that’s fine. Obviously, you don’t want it used illegally, or you don’t want any of your personal information to be exploited for something negative. (Participant 6 [39-year-old female])

I don’t think it’s against the realm of possibility to have a biochemical weapon that only works on X gene, or a specific race, or anything like that. That would be a big “no.” That’s extremely problematic. (Participant 17 [33-year-old female])

In discussing nonresearch purposes, about half of the participants stated that use by law enforcement was not acceptable, particularly if genetic information could be racially biasing. The other half felt that use by law enforcement was acceptable, depending on the specific use. For example, identification of missing persons was acceptable, but wrongfully planting DNA to frame an individual was not. Participants were generally not in favor of cloning, though some reported that it would depend on the purpose; cloning organs for transplant would be an

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acceptable use. Participants similarly felt that use for product development would depend on the situation. Some felt that internal product development by the company is acceptable, but external product development is not.

I’m thinking if they’re using it – like sometimes you hear about studies where the group, all African-Americans or this way or that way. Coming up with negative connotations about African-Americans based on DNA. I don’t know how they would do that, but you do hear sometimes negative comments about people of color…. Even though I’ve never committed a crime, I would not want my DNA submitted as, “Hey, let’s just run this through and see what we come up with.” … Hey, people make mistakes in testing anything. I would not want it used in that form. (Participant 5 [63-year-old female])

I just I don’t wanna feel like I’m a criminal, or that my information could be in a database… if the cops just walked up to you and they said, “Okay, let me get your DNA,” you would be like, “No.” You know you didn’t do anything, but still, you’re gonna be like, “No. This feels wrong. I didn’t do anything. Why?” (Participant 19 [36-year-old male])

No, cause I guess I really don’t understand what kind of products, whether it’s food, medicine, lotion. I just don’t know. I would just have to say no. Cause I don’t know, so I would say no to products. (Participant 9 [62-year-old female])

Yes…. When I talk about products, I mean everything from prescription medicines to shampoo… Just being African-American, I’ve ran into certain things and products that does not work well for African-Americans. If you can use – use my DNA to find the right products that can work best for a certain type of people, by all means, go for it. (Participant 16 [29-year-old male])

Another theme about secondary use that emerged in over half the interviews was that consent or notification should be required for use. Many participants also expressed concern about how their information or sample might be used and uncertainty/lack of control about the possible array of secondary uses.

When it’s used for these other purposes, I wanna know about it… I did [genetic testing] because I wanted to know where’s my family from, period. If you’re doing it for these other purposes, then I’m, “Well, what is it for?” (Participant 10 [47-year-old female])

Half of the participants did not know whether they had the option to opt out of secondary uses by the DTC GT company. The other half believed or knew with certainty that there were opt-out options. Regardless of their knowledge, participants strongly felt that they wanted opt-out options for all secondary data use. Some expressed that they would not have done the test if they knew there was not an opt-out option.

Participants were asked if it is possible to identify them based on a DNA sample alone. Over half felt that reidentification would be possible in conjunction with some sort of database. Others reported that they did not think they could be reidentified from a DNA sample alone. Regardless of their response, when asked if reidentification would be acceptable to them, most reported that this would not be an acceptable action to them. Some stated that it would only be acceptable if consent or notification were given. Those who said it would be acceptable typically gave examples of law enforcement involvement for the identification of a missing person or violent crime event.

Yeah. I believe so, cause I think when you’re born in a hospital, that they store your information. You’re being registered somehow… It wouldn’t shock me if the government got my Social, a little sample of my blood, sample of my hair, skin, and maybe a tooth. (Participant 16 [29-year-old male])

Half of the study participants were unsure if DTC GT companies can sell consumer data. Many did not think it was possible but were unsure. A small proportion of participants were certain that companies could sell consumer data. Regardless of their knowledge, most participants noted that DTC GT companies selling data/samples is not acceptable, particularly without express consent by the consumer. Others felt that selling was acceptable if samples or data were used for good reasons such as research. Some participants thought that selling data to other parties is a logical step that DTC GT companies would make.

I’m not in support of that… If you are selling my information, you are profiting from that. Then I probably wouldn’t have a say so on who you sold it to. I’m not gonna give a blanket consent to sell my information. (Participant 18 [44-year-old male])

Genetic Discrimination

None of the study participants were familiar with the Genetic Information Nondiscrimination Act (GINA) [32]. Interviewees were read a short description about GINA and asked if they felt that it was possible to be denied insurance based on a DTC GT result. Almost all of the participants felt that it would be possible to be denied insurance, many suggesting the possibility that DTC GT companies could share information with insurance companies.

I don’t put anything past the insurance company for trying to not insure you because if you have something, or your ethnicity is prone to something, then they don’t wanna insure you. (Participant 9 [62-year-old female])
Participants were asked if the interview changed their thoughts about how their DNA could be used for reasons other than providing them with their direct test results. Many participants expressed that they were made to think more about their experience with DTC GT or that they were happy to be more informed, most specifically mentioning new knowledge about GINA. Almost half of the participants did not have changed thoughts and reflected that they had a pragmatic approach to testing and had already considered the ideas presented in the interview.

New Concerns

While participants were made to think more about the issues discussed, the majority expressed no new concerns after the interview. Other interviewees had a range of new concerns, including worries about secondary uses such as law enforcement, selling, and cloning, language in the privacy policy, and sharing practices. Interestingly, some participants noted new concerns throughout the interview but did not bring them up when asked directly if they had new concerns.

Different Company Practices

Participants had a wide range of ideas for different company practices. The most common requested change was increased transparency about research and secondary data uses by the DTC GT company. Additionally, participants wanted help interpreting the language in the privacy policy and their results. Others wanted privacy policy updates. Some of the research participants felt happy with their DTC GT experience and did not have suggestions for company practices.

Additional Themes

Trustworthiness in the Medical Community versus DTC GT Company

When prompted to reflect on their level of trust in the medical community versus DTC GT companies about having DNA information, the majority of participants expressed more trust in the medical community. The reasons provided included that the medical community has more regulations and are obligated to help people. However, four participants said they had more trust in a DTC GT company having their DNA sample or data because they believed the company would not use their data without permission, the company has greater data protection, or the medical community is more likely to exploit patients. Four participants expressed equal concern about their genetic information being in the hands of either party. Interestingly, of the participants who reported more trust in DTC GT companies, one had consulted with their medical provider before pursuing DTC GT. The three others who consulted with healthcare providers before pursuing testing expressed more or equal trust in the medical community.

When I think of the two, this one always comes down to money for me. I believe more of [company] trying to help the people. I’m not saying hospitals aren’t trying to help anyone, but if I knew that the hospital that I go to is using my information, using my stuff, I don’t know. Now, you got me thinking. Because every year when I go get a physical, I get blood tests and pee tests and stuff like that since it’s pretty much free underneath my wellness check. I just cannot see the hospital using my information for anything good. … I feel like I can see [company] doing something good compared to the hospital… I just get a bad feeling when I think of the hospital. (Participant 16 [29-year-old male])

I would be, I think, less concerned about my health care provider using the information. I know going through, dealing with a couple of different medical issues, they would have asked if I was okay with my samples being stored for future testing… I think most health care providers goal … is better health care. I absolutely, I trust them a lot more for that. (Participant 18 [44-year-old male])

It’s a health care entity, and I feel like they’re less likely to go into non-health-related research. Yeah, I feel like it’s a little safer. That it will end up at Apple or anything like that. I also feel like there’s just a lot more policies and laws in place that hold hospitals accountable for where data goes… so it feels a lot safer through a healthcare establishment than through [GT company]. (Participant 7 [25-year-old male])

Racial Themes

One theme that came up throughout the interview in over half of the participants was their consideration for the African-American community in general. This racial consideration appeared in test selection and motivations for testing, reflections on acceptability of research, and unexpected outcomes of testing which challenged participants’ personal identity. Participants referenced slavery history, negative racial profiling, and poignant misconduct examples like the treatment of Henrietta Lacks and her family. Racial considerations arose frequently in discussion about the acceptability of law enforcement use of DTC GT databases.

You didn’t have a lot of easy ways to find things especially if you’re trying to dig through records in the south pertaining to African-Americans because you just ran into a lot of stops. If something wasn’t transferred or kept or made a copy of sometimes you only get back one generation or two generations, and then everything was to the point it was written in Bibles, like you didn’t really see hard copies. (Participant 11 [43-year-old female])
Participants generally had a positive regard for and were motivated to pursue genetic testing. Some expressed reservations or negative issues related to participation in DTC GT, but this did not outweigh their decision to pursue testing. Other research related to both DTC GT and clinical testing has also demonstrated this general positive regard [33]. Although participants had not necessarily completed DTC GT, similar positive interests and reservations have been expressed through public surveys [34–36].

An overarching theme that came across throughout the interviews was the altruistic attitude that uses of genetic information for “good” was acceptable to the participants. This manifested both in the positive attitude toward research contributing to the betterment of society and the negative attitude that detrimental or illegal uses and uses negatively targeting a specific racial or ethnic group were not acceptable. This aligns with themes brought up in previous research of African-American’s fears of ill intent in considering participation in research as well as an overriding duty to participate in research to add diverse representation [37, 38].

The study assessed participants’ level of trust in the medical community versus the DTC GT company in using data for secondary uses. While the majority of participants expressed more trust in the medical community, four participants trusted DTC companies more. Reasons for trust levels varied but reflected a documented research finding of populations of color’s distrust of the medical community, particularly among the Black or African-American community [38–40]. Distrust has been tied to historic and continued injustices in studies, fears of study processes and outcomes, and possibility of findings purporting biases leading to genetic discrimination [38]. One group of African-American nurses suggested that genomic education, distrust, cultural competency, and the role of Black healthcare organizations were factors that impede, support, and/or promote genetics and genomics knowledge in practice and participation in research [41].

Participant responses in this study compared to the parallel data collected by Mladucky et al. [22] revealed more similarities than differences. Participants were aware that secondary uses of their data by the company was a possibility but had little concrete knowledge about company practices. The two cohorts shared positive general thoughts about genetic testing and research, but held that consent should be required, and deidentification is desired when data are used for research purposes. This clarifies consumer expectations of data usage and protections and supports the need for consent and transparency when consumer genetic information is used for secondary purposes [42].

One notable difference between cohorts was that racial commentary was not addressed by any of the participants in the Mladucky et al. [22] cohort where over half of the participants in this study brought up racial considerations across all areas of the interview. One such example was participants’ reflections on the acceptability of law enforcement use of DTC GT databases. No one in the Mladucky et al. [22] cohort brought up concerns of racial profiling or discrimination, where a few participants in this study did. These concerns may reflect general experiences of living in a racialized society, including disproportionate incarceration rates among African-Americans.
[43], less trust in law enforcement and the justice system [44], and increased police violence against African-Americans [45]. Note that these interviews were conducted before increased awareness of racial injustices, particularly by law enforcement, was brought to the world platform in the summer of 2020 [46].

Considerations of African-Americans also reflected a sense of community in this study. Research has suggested that historically oppressed groups such as African-Americans may have an increased sense of community and resilience compared to other groups [47]. Our findings of sense of community are consistent with other themes of ancestral origin and kinship being expressed by DTC GT consumers on online discussion forums [48]. This overarching sense of community appears to be strong among these users.

This research reflects useful themes for consumers, healthcare providers, and DTC GT companies to consider. Consumers may benefit from broader considerations of the possible implications in completing DTC GT and might engage with knowledgeable communities before proceeding with testing [48]. Healthcare providers can address benefits, limitations, and risks in DTC GT in discussions with patients considering testing. This research also highlights African-Americans’ concerns with the healthcare system, and providers should strive to be sensitive about these concerns and offer greater transparency about research and secondary uses themselves.

Similarly, DTC GT companies can consider participants’ desire for greater transparency in company practices, more accessible language in privacy policies, and greater support for customers after testing is completed. Since the summer of 2020, racial injustices across all aspects of society have been critically examined. DTC GT companies have issued statements reflecting on their role in racial inequality in genetics [49, 50], and genetics professionals have offered suggestions about how to best serve underrepresented communities. These include diversification of leadership, demonstration of the value of their service to underrepresented populations, recruitment of people of color in research studies, and consideration of compensation for data [51].

Avenues for future research include interviewing or surveying potential consumers who did not choose to pursue DTC GT. These participant's insights may provide a more balanced view of attitudes toward GT and DTC GT companies and a richer understanding of barriers to precision medicine. Other future directions include expansion among other underrepresented populations and expanding the survey to encompass broader trust in various institutions using genetic information for secondary uses, including hospitals, testing laboratories, and government agencies.

Limitations of this research include a recruitment bias among individuals registered in ResearchMatch. Participants were already open to participating in research and may not capture the average consumer’s views on data usage for research. Our sample was also disproportionately college educated and female compared to the general population. However, this is representative of the DTC GT customer population as a whole [52]. Furthermore, in comparing results of the cohort presented in this research and the Mladucky et al. [22] cohort, one must consider changes to the interview guide. In the Mladucky et al. [22] study, examples of secondary uses of law enforcement, product development, and cloning were asked about as a group, and in this study, participants were asked about each example separately. Interviews were also conducted by different interviewers, and there was a 1-year time lapse between data collection.

Unprompted themes reflected by research participants such as altruism, duty to participate, mistrust in potential research applications, concerns about privacy, use by law enforcement, and community considerations have been reflected in other research studies. The intent of this study was not to reiterate these findings, rather allow themes to emerge organically. Alignment of these themes through personal narratives of African-Americans has not been directly documented in previous literature and highlights the importance of including underrepresented perspectives in the field of genetics and DTC GT. As DTC GT continues to grow, it is imperative to capture the diverse consumer experience as it relates to all aspects of DTC GT. Dialogue about DTC company secondary uses and consumer privacy can create more informed consumers. The information may also help healthcare providers consider institutional practices relating to secondary uses in discussions of DTC GT with patients. Finally, DTC GT companies can draw on consumer experience to improve adequacy of their informed consent, provide products that meet consumer expectations, implement measures to enhance company practices supporting racial equality, and strive for transparency in their practices of secondary uses.

Themes presented in this paper may help guide broader conversations about participation in other precision medicine applications. Though racial and ethnic disparities in healthcare are not new, this research adds additional facets to the complex conversation [53].
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Study protocols and human subjects’ considerations were reviewed and approved by the Institutional Review Board (IRB) at the University of Utah, approval number IRB_00114603. All participants were read a consent script, had the opportunity to ask questions, and provided voluntary verbal informed consent to participate in this research. This verbal consent process was approved by the IRB at the University of Utah.

Conflict of Interest Statement

Emily Ziegler, Bonnie Baty, Janessa Mladucky, Rebecca Anderson, and Jeffrey Botkin declare that they have no conflict of interest.

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Statement of Ethics

Emily Ziegler: data collection, analysis and interpretation, and wrote and revised drafts of the manuscript. Bonnie Baty: conception of work, interviewer training, analysis and interpretation, critical review and revision of manuscript, and final approval of manuscript. Janessa Mladucky: conception of work, data analysis and interpretation, critical review and revision of manuscript, and final edits and approval of manuscript. Rebecca Anderson and Jeffrey Botkin: conception of work, critical review and revision of manuscript, and final approval of manuscript.

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Author Contributions

Emily Ziegler: data collection, analysis and interpretation, and wrote and revised drafts of the manuscript. Bonnie Baty: conception of work, interviewer training, analysis and interpretation, critical review and revision of manuscript, and final approval of manuscript. Janessa Mladucky: conception of work, data analysis and interpretation, critical review and revision of manuscript, and final edits and approval of manuscript. Rebecca Anderson and Jeffrey Botkin: conception of work, critical review and revision of manuscript, and final approval of manuscript.

Data Availability Statement

The interview guide is available in the online supplementary materials. Interview transcripts will not be shared due to concerns over identifiability of study participants. Requests for and questions about raw data taken from interviews can be directed to the corresponding author.
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