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Privacy Concerns About Genetic Testing: Does Ethnicity Matter?

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Abstract

The direct-to-consumer genetic testing market is predicted to reach \$340 million by 2020 (Seward, 2018). DTC genetic tests (DTC-GTs) are DNA kits purchased and taken by consumers in the privacy of their homes, allowing them to know about their ancestry, trait/disease propensity, etc. Although, many companies state in their privacy policies that they share genetic information with third parties, it is not evident that customers understand the full implications of how their information will be used e.g., for research or law enforcement. Prior research has found some ethnicities have low awareness of DTC-GTs e.g., African Americans and Hispanic Americans (Salloum et. al, 2018) but it is not clear if this also impacts their privacy concerns. The role of ethnicity is important due to historical reasons for e.g., the case of Henrietta Lacks (Rao, 2016), medical experimentation on slaves, and the Tuskegee Syphilis Study (Gamble, 1997). This research aims to address this research gap, by examining the impact of ethnicity and attitudes toward privacy on consumers' purchase of DTC-GTs. After reviewing literature, the researcher developed a conceptual model and testable hypotheses. The researcher then conducted an online survey of 103 adult participants and deployed advanced statistical techniques, such as t-tests and a correlation analysis, for data analysis. Based on the study's findings, non-users of genetic testing services do not possess higher levels of privacy concern, regarding sharing their genetic information with DTC-GTs, than users. Also, while African American participants were more aware of historical instances of unethical medical experimentation, the study revealed they are unlikely to have higher privacy concerns about genetic testing than other ethnic groups. This awareness is also unlikely to deter them from purchasing DTC-GTs. This research contributes to our understanding about privacy-related challenges in the rapidly evolving DTC genetic testing market. Using the ethnicity lens for this research is especially insightful for genetic testing companies as well as policy makers.

Introduction

According to the MIT Technology Review, over 26 million people have shared their genetic information with one of four leading direct-to-consumer (DTC) genetic testing companies. In 2018, the same number of DTC genetic tests were purchased as all of the previous years since 2012 combined. At this rate, the MIT Technology Review predicts these companies, which include AncestryDNA, 23andMe, Family Tree DNA, and MyHeritage, will possess the genetic information of over 100 million people in the next two years (Bursztynsky, 2019). DTC genetic tests are DNA kits purchased and taken by consumers in the privacy of their homes. By 2020, the DTC genetic testing market is predicted to reach a market revenue of \$340 million (Seward, 2018). The origins of this rapidly growing market trace back to when entrepreneur Bennett Greenspan and researcher Dr. Michael Hammer founded Gene by Gene, the first commercialized DNA ancestry testing service, in the late 1990s. Family Tree DNA, a subsidiary of Gene by Gene, now competes with market giants, AncestryDNA and 23andMe, to provide consumers with unique opportunities to discover their ethnicities, long-lost relatives, and propensities to carry certain genetic disorders (Brooke, 2018).

An unexpected result of DTC genetic testing has been the offspring of sperm donors discovering their biological fathers through 23andMe or Ancestry.com. For example, NBC News spoke with over a dozen sperm donors, their children, and families about how DTC genetic tests brought them together. Peter Ellenstein, a fifty-seven-year-old theater director in Los Angeles,

donated sperm decades ago. He recently met 20 of his biological children through DTC genetic tests and other online tools. Ellenstein and his children found uncanny similarities between themselves, such as their brash sense of humor, love for puns, and clumsiness (Chuck, 2018).

While some sperm donors have welcomed the opportunity to meet their biological children through DTC genetic testing, many prefer to remain anonymous and view these tests as an invasion of privacy. This past January, CBS News interviewed Danielle Teuscher, a woman who received a “cease and desist” letter from Northwest Cryobank, the sperm bank from which she had purchased to conceive her daughter. When Teuscher saw a DNA match on her five-year-old daughter’s 23andMe profile listed as open to messaging, she messaged them stating, “I don’t want to cross any boundaries. I just want to let you know that we are out here and we are open to contact if you are.” In response, the relative messaged, “I don’t understand.” Soon after, Teuscher received the letter from Northwest Cryobank warning her not to contact the donor or attempt to “learn more information about his identity, background or whereabouts.” Northwest Cryobank viewed Teuscher’s act of messaging her donor’s relative on 23andMe as a breach in the contract she had signed online and a violation of the donor’s genetic privacy (“Woman uses DNA test, finds sperm donor”, 2019).

Unintentionally, genetic test results are also helping to solve decades-old cases. Last year, police solved the “Golden State Killer” case through matching a DNA sample of the suspect, former police officer Joseph James DeAngelo, from an old crime scene with the DNA of his relatives found on GEDmatch. GEDmatch, an open-source genetic database with between 900,000 and 1,000,000 users, allows users to “upload and share their information for free, making it accessible to law enforcement, researchers and private citizens alike” (Ducharme, 2018).

These examples illustrate how consumers’ genetic information stored in public databases has developed into an increasingly public form of personally identifiable information. Genetic information can now be linked to an individual not only through their own DNA samples, but also through the genetic information they share with others. While genetic testing allows consumers to attain a deeper understanding of themselves and helps connect them with family members, it also raises a number of ethical and legal conundrums, especially given that there are no clear guidelines regarding the privacy of consumers’ genetic information.

Further, it is unclear whether there is widespread awareness in the U.S. of privacy laws, violations of privacy, and informed consent surrounding genetic privacy. Current legislations pertaining to genetic privacy include the Health Insurance Portability and Accountability Act (HIPAA) of 1996 and Genetic Information Nondiscrimination Act (GINA) of 2008. In addition, the Common Rule of 1981 establishes standards for research involving human subjects and obtaining informed consent from participants. Notable historical examples of medical research in the U.S involving violations of informed consent include the gynecological studies of Dr. J. Marion Sims (1845 - 1849), the case of Henrietta Lacks (1920 -1951), and the Tuskegee Syphilis Study (1932 – 1972). A gap in research exists regarding if consumers’ awareness of these events influences their willingness to consent to participating in genetics research or take DTC genetic tests. This research studies the role of privacy concerns in consumers’ adoption of genetic testing services. The research also examines the relationship between ethnicity and the adoption of genetic testing services.

Literature Review

Genetic Privacy Concerns

Legislations

In the U.S., the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule sets standards for the protection of individuals' personal health information. This legislation permits companies to store and use consumers' personal health information for research purposes as long as the data is anonymized to prevent the identification of specific individuals. Since genetic data is classified as personal health information, the sharing of consumers' genetic data with third parties is legal in the U.S. However, the fact that an individual's genetic code can always be linked back to them, if a second DNA sample is available, invalidates the notion that the data is completely anonymized (Seward, 2018). As a result, Seward recommends "these threats to patient privacy can be mitigated through the institution of regulations that offer genetic testing-specific requirements for deidentification and to ensure that genetic data held by DTC companies are classified as PHI and protected by the Privacy Rule" (p. 485).

Currently, the only legislation in the U.S. that directly pertains to genetic privacy is the Genetic Information Nondiscrimination Act (GINA) of 2008. GINA protects U.S. citizens from genetic discrimination based on health insurance and employment. This law amends HIPAA to include genetic information as a type of health information. As part of GINA, health insurers are prohibited from requesting or requiring individuals or their family members to provide genetic information or undergo genetic testing. Employers are also prohibited from using genetic information in employment decisions ("The Genetic Information Nondiscrimination Act of 2008", 2017).

In regard to the consent of participants in genetics research, the "Common Rule" of 1981 was enacted by the U.S. Department of Health and Human Services to establish standards for research involving human subjects in the U.S. Under the Common Rule, researchers must obtain the informed consent of participants and "must provide the research subject with information about the potential risks and benefits of participating in research" (Rao, 2016). As a result, informed consent presents the issue of genetic privacy in the DTC genetic testing market. One topic this research attempts to address is the relationship between knowledge of the above-mentioned legislations and consumers' willingness to consent to genetics research. In addition, this would also provide insights on the level of awareness of such legislation.

Informed Consent

In the DTC genetic testing market, informed consent refers to the extent to which customers of genetic testing companies understand the purposes for which their genetic information will be used by and shared with third parties. While most companies state in their privacy policies that they share genetic information with third parties, it's unclear to many customers the exact purposes for which their genetic information will be used.

For instance, 23andMe recently implemented a marketing campaign that offered customers with two DNA testing options, a "research" edition and a "traditional" edition. The research edition is priced lower and offers fewer services than the traditional edition. This leads customers to assume the research edition would utilize their genetic information for research purposes, while the traditional edition would not. However, both editions use customers' genetic

information for research purposes, which customers miss unless they carefully read the privacy policy (Seward, 2018).

In addition, Anderson and Agarwal (2011) argue that the willingness of individuals to consent to sharing personal health information, for the purpose of electronic storage, is affected by different factors, such as health status and emotion, and likely to change over time. For example, the authors found that individuals who experience negative emotions regarding their health status, like anger, sadness, or anxiety, are more willing to provide access to their personal health information. They concluded that since individuals' health status and emotions change over time, "consent granted by individuals should be valid only for a specific time" (487). This relates back to the DTC genetic testing market, because individual customers' attitudes toward their genetic information being used in research can change over time.

The fact that companies can edit their privacy policies, at any point in time, presents another concern for customers (Rosenbaum, 2018). As a result, an important part of gaining consent from customers is respecting their right to withdraw their genetic information from databases. While major genetic testing companies, like AncestryDNA and 23andMe, offer customers' the opportunity to withdraw their consent at any time, through their account settings, this may not apply to genetic data already processed before the withdrawal. For example, 23andMe states the following in their privacy policy,

"Any research involving your data that has already been performed or published prior to your withdrawal from 23andMe Research will not be reversed, undone, or withdrawn" ("23andMe Full Privacy Statement", 2018).

This reinforces why it's critical for customers to carefully read privacy policies, before participating in genetic testing services, and stay up-to-date on any revisions to these policies. Another question this research addresses is the extent to which consumers are aware of and read privacy policies of DTC genetic testing services.

Cybersecurity Risks

Cybersecurity breaches present another concern for users of genetic testing services. On June 4, 2018, a private researcher notified the Chief Information Security Officer of MyHeritage that he uncovered a file, on a private server outside of MyHeritage, containing the email addresses and passwords of 92 million users. The same day, the company posted a statement on their blog stating the intrusion was limited to user email addresses and they had "no reason to believe that any other MyHeritage systems were compromised." MyHeritage explained that customers' credit card information is stored on third-party billing providers, such as PayPal and BlueSnap. Users' genetic information and family trees are "stored by MyHeritage on segregated systems, separate from those that store the email addresses, and they include added layers of security." To reduce the likelihood of data breaches, the company is working toward providing users with a two-factor authentication feature ("MyHeritage Statement About a Cybersecurity

Incident”). Accordingly, this research seeks to evaluate the extent to which consumers of DTC genetic testing services are concerned about the privacy and security of their genetic information.

Informed consent and cybersecurity risks are aspects of privacy concerns that would likely impact the purchase of DTC genetic testing kits. In fact, privacy has been defined as “the claim of individuals, groups, or institutions to determine for themselves when, how, and to what extent information about them is communicated to others” (Malhotra, Kim, & Agarwal, 2004). Based on the above, the following hypothesis is offered:

H1: The higher the privacy concerns, the lower the propensity to purchase DTC genetic testing kits.

Ethnicity

In 2018, a team of researchers at Vanderbilt University conducted a literature review about individuals’ concerns about genetic privacy and factors influencing these concerns. The team analyzed 53 studies involving 47,974 participants. During the literature review, the researchers found that “in almost all studies reporting differences in perspectives by race or ethnicity, non-White individuals had greater concerns about privacy, including more desire for control over use of their data and less willingness to share data than their White counterparts” (Clayton, Halverson, Sathe, & Malin, 2018).

In another study conducted in 2011, ethnic differences in perceived risks about participating in psychiatric genetic studies found that African Americans were more likely to be very concerned about the loss of privacy than White Americans. Of the 1,253 patients with bipolar disorder surveyed, 41.9% of African American participants reported being very concerned, while 24.6% of White participants reported being very concerned (Nwulia, Hipolito, Aamir, Lawson, & Nurnberger, 2011). A 2015 study, which surveyed surrogates and patients about participating in critical illness genetic research, found that African Americans were more likely to be unreceptive to participating in genetic research. They were also more likely to view the loss of confidentiality, discrimination based on genetic information, and genetic information being shared with insurance companies as major concerns of participating in genetic research (Freeman et al., 2016).

Similarly, in a 2000 study, which assessed public reactions to scientists’ announcement of completing the Human Genome Project, revealed African Americans were more likely to report negative reactions than White Americans. The study surveyed 407 Maryland residents with 66.7% of African American participants and 34.6% of White American participants having initial negative reactions about the project. At the turn of the century, privacy, discrimination, and human cloning were common concerns participants had about genome mapping (Tambor, Bernhardt, Rodgers, Holtzman, & Geller, 2002). This study investigates whether ethnic differences have an impact on consumers’ privacy concerns with regard to DTC genetic testing services and therefore, on their purchase of such services. In particular, we investigate whether knowledge of historical events that have undermined the privacy of African Americans in medical testing, could be a reason for African Americans having greater privacy concerns.

According to Gamble (1997), feelings of being undervalued in American society and knowledge of historical instances of unethical medical experimentation lead African Americans to be more distrustful of and less willing to participate in medical research. For instance, the Tuskegee Syphilis Study, provides an example of a historical event that “predisposed many African Americans to distrust medical and public health authorities.” During the government study, which took place between 1932 and 1972, 399 African American men living in Macon County, Alabama, were denied treatment for syphilis, so researchers could document the natural progression of the disease. The subjects were not informed of the purpose of the study or of their condition.

While the study greatly impacted many African Americans’ attitudes toward medical research, Gamble argues this “mistrust predated public revelations about the Tuskegee study” and “the narrowness of such a representation places emphasis on a single historical event to explain deeply entrenched and complex attitudes within the Black community.” Instead, she states African Americans’ apprehensions date back to the antebellum period, when slaves and free African Americans were used as subjects for medical experimentation. During this period, slaves were considered property by the government and denied the legal right to refuse to participate (Gamble, 1997).

An example of medical experimentation on slaves were the gynecological studies conducted by Dr. J. Marion Sims, the father of modern gynecology. Between 1845 and 1849, Sims operated on three enslaved women in Alabama to develop a cure for the vesicovaginal fistula. Each woman “underwent up to 30 painful operations” and “Only after his experimentation with the slave women proved successful did the physician attempt the procedure, with anesthesia, on White women volunteers.” After the Civil War, African Americans continued to experience medical exploitation. In the late 19th century, a grave robbing ring operated in Philadelphia, which “provided bodies for the city’s medical schools by plundering the graves at a Black cemetery” (Gamble, 1997).

The case of Henrietta Lacks (1920 - 1951) provides another example of African Americans being utilized as subjects in medical research without consent. Lacks, an African American woman who died from cervical cancer, was the source of the HeLa cell line, the first immortalized cell line in medical research. Her cancer cells were essential to scientific advancements, such as the polio vaccine, cloning, in vitro fertilization, and gene mapping. After her death, a sample of cells were shipped from the John Hopkins Hospital to the lab of cancer researcher Dr. George Gey and subsequently sold to labs around the world. The researchers did not obtain consent from Lacks or her family to use her cells in research. In 2013, researchers published the HeLa cell line genome in open-access databases. This sparked a debate over Lacks’ family’s right to privacy, regarding their shared genetic sequence with her cells (Rao, 2016).

Reverend Floyd Tompkins of Stanford University Memorial Church once stated the following about African Americans’ attitudes toward medical research:

“There is a sense in our community, and I think it shall be proved out, that if you are poor or you're a person of color, you were the guinea pig, and you continue to be the guinea pigs, and there is the fundamental belief that Black life is not valued like White life or like any other life in America” (qtd. in Gamble, 1997).

Historically, feelings of being exploited and treated as though their lives don't matter, have resulted in many African Americans being more distrustful and less willing to participate in medical research. Since genetic information is a form of health information, these existing attitudes may have implications for African Americans' attitudes towards genetic privacy. This study investigates whether ethnic differences have an impact on consumers' privacy concerns with regard to DTC genetic testing services and therefore, on their purchase of such services. In particular, we investigate whether knowledge of historical events that have violated the privacy of African Americans in medical testing, could be a reason for African Americans having greater privacy concerns.

H2: African Americans will be more aware than other ethnicities of unethical medical testing conducted on African Americans in the past.

H3: Higher awareness of unethical medical testing instances will result in African Americans having higher privacy concerns about genetic testing.

Research Methodology

This study's research objectives are (1) To understand attitudes towards genetic testing services; (2) To evaluate privacy concerns related to genetic testing services; (3) To examine the role of ethnicity in privacy concerns related to genetic testing services. To answer these research objectives, a literature review of secondary sources relating to the direct-to-consumer (DTC) genetic testing market, current privacy issues within the market, and the ethnic implications of medical research, was conducted. After that, a 27-question survey was developed in Qualtrics to gather primary data and distributed to participants online through a reusable link. The survey includes attitudinal questions, demographic questions, and questions built from established scale items for measuring privacy concerns (see Appendix A). In addition, the study utilizes a correlational research design to measure the statistical significance of relationships between four independent variables and one dependent variable. The independent variables measured include (1) privacy concerns, (2) ethnicity, (3) knowledge of privacy policies, and (4) knowledge of unethical medical research. The dependent variable measured is the adoption of genetic testing services.

Furthermore, the sample population of this study was defined based on age as adults ages 18 and over. Both users and nonusers of genetic testing services were surveyed, and 120 responses were obtained. Of these, 17 responses had to be removed from the data, yielding a final sample of 103 participants. Responses were removed from the data due to respondents selecting they did not consent to participating in the study, they had no prior awareness of genetic testing services, or they had no prior awareness of any genetic testing brands. Most of the study's participants included students at Kennesaw State University, where the researcher attended school, and within her personal and professional network. As a result, a convenience sampling technique was implemented to gather participants.

The two largest age groups in the sample included people ages 18 to 24 (72%) and over the age of 65 (10%) (see Figure 1). In addition, the two largest ethnic groups included African Americans (39%) and White Americans (47%) (see Figure 2). Based on gender, women comprised 69% of the sample and men comprised 31% of the sample (see Figure 3). The sample population was also composed of 17% users of genetic testing services and 83% non-users of genetic testing services (see Figure 4).

Data Analysis and Findings

The study's findings revealed insights on participants' awareness of genetic testing brands, the brands they purchased, satisfaction with their purchases, perceptions of how customers' genetic information are used by companies, and awareness of privacy policies. AncestryDNA had the highest brand awareness at 101 out of 103 participants, or 98.1%. Next, 80 participants, or 77.7% , were aware of 23andMe (see Figure 5). Of the 18 participants who had purchased DTC genetic tests, 14 participants had purchased AncestryDNA and 4 had purchased 23andMe. Moreover, 15 of the 18 users of genetic testing services reported being satisfied with their purchases. The majority of users (72.2%) also did not believe DTC genetic testing companies use consumers' genetic information for only the purposes they advertise. When asked about their awareness of privacy policies concerning genetic information, nearly half of the total participants were aware of HIPAA (49%), but less than a fifth (14%) were aware of GINA (see Figures 6 and 7).

H1

This study's first hypothesis states, "The higher the privacy concerns, the lower the propensity to purchase DTC genetic testing kits." To determine if non-users of genetic testing had higher privacy concerns than users, an independent samples t-test was conducted on SPSS. The t-test utilized one nominal variable and one interval variable. The nominal variable was measured by question A3, which inquires, "Have you ever purchased a genetic test?" This variable was used as the grouping variable for the t-test. Participants responded either "Yes" or "No" to this question, with nominal categories of 1 and 2 assigned to each response, respectively. Participants who answered "Yes" made up the group of users of genetic testing services, while participants who answered "No" made up the group of non-users of genetic testing services.

The two primary reasons non-users had not purchased a genetic test included price (37.9%) and having no desire to learn about their genetic information (37.9%). Privacy issues were the third most cited reason (17.5%). Other reasons included participants not seeing the benefits in purchasing a genetic test, never making time to purchase one, already seeing family members' results, and feeling skeptical of the tests' accuracy (see Figure 8).

In addition, the t-test measured users and non-users' privacy concerns using a summary score of their responses to questions C1 to C5. In these questions, participants rated statements about their attitudes toward genetic privacy on a scale from 1 to 7. A rating of 1 corresponded to strongly disagreeing with the statement, while a rating of 7 corresponded to strongly agreeing with statement. To calculate the summary score in SPSS, a new variable was computed from

participants' mean responses to questions C1 to C5. To ensure consistency in measuring this privacy score, some of the variables' scales were reverse coded, specifically variables computed from C4 and C5.

Based on the null hypothesis, there would not be a significant difference in the mean privacy scores of the two groups, users and non-users. In contrast, the alternative hypothesis predicted there would be a significant difference between the two groups' privacy scores, with non-users having a greater privacy score. Since both the significance values in the Independent Samples Table are greater than 0.05, the t-test provides no evidence to reject the null hypothesis (see Table 1). For instance, the significance value for Leven's Test for Equality of Differences is 0.344 and the two-tailed significance value is 0.995.

Consequently, null hypothesis is accepted, which reveals an insignificant difference between the users and non-users' privacy scores. Based on the Group Statistics table, users had a mean privacy score of 5.4618, while non-users had a privacy score of 5.4605. The difference between these scores is negligible. As a result, the t-test demonstrates users and non-users' of genetic testing services possess similar levels of privacy concern. Of the 103 participants who answered question A3, 18 were users of genetic testing services and 85 were non-users.

H2

The second hypothesis of this study states, "African Americans will be more aware than other ethnicities of unethical medical testing conducted on African Americans in the past." The researcher utilized another t-test to compare the level of awareness between the study's two largest ethnic groups, African-American and White participants. In questions C8 to C10, participants were asked to select the degree of their awareness of the Henrietta Lacks story, Tuskegee Syphilis Study, and gynecological studies of Dr. J. Marion Sims. The questions were based on a six-point Likert scale with responses ranging from "Definitely Unaware" to "Definitely Aware." A summary score of these questions was computed to measure participants' overall awareness of these events using a six-point interval scale. A value of 1 was designated to "Definitely Unaware", while a value of 6 was designated to "Definitely Aware." Ethnicity was measured by D3 using a nominal scale, which asked respondents to either select or describe their ethnic background.

The null hypothesis of this t-test argues there will be insignificant differences between African American and White participants' awareness of unethical medical testing conducted on African Americans. On the contrary, the alternate hypothesis asserts there will be a significant difference between African-American and White participants awareness of unethical medical testing conducted on African Americans. Based on test's results, there's a significant difference between African American and White participants' awareness of these events (see Table 2). For example, both significance values in the Independent Samples Table are equal to 0.000 and thus, significant at the 0.05 level.

Of the 103 participants who answered questions C8 to C10, there were 40 African American participants and 49 White participants. Participants who identified as "Afro-Caribbean" or "Black" were included in the group of African American participants. On a scale

of 1 to 6, the mean awareness score of African American participants was 3.15. This revealed African American participants to be “Slightly Unaware” of unethical medical testing conducted on African Americans. In contrast, White participants had a mean awareness score of 1.50, or “Somewhat Unaware.” On average, African American participants were more aware of the Henrietta Lacks story, Tuskegee Syphilis Study, and gynecological studies of Dr. J. Marion Sims than White participants.

H3

This study’s third hypothesis predicts, “Higher awareness of unethical medical testing instances will result in African Americans having higher privacy concerns about genetic testing.” To test this hypothesis, the researcher conducted a t-test and correlation analysis. The t-test compared African American and White participants’ mean privacy scores. According to the null hypothesis, there would not be a significant difference between African American and White participants’ privacy scores. In contrast, the alternative hypothesis argues there would be a significant difference between African American and White participants’ privacy scores.

Based on the t-test results, there was an insignificant difference between African American and White participants mean privacy scores (see Table 3) In the Independent Samples Table, both significance values were greater than 0.05 at 0.535 and 0.467, respectively. On a scale from 1 to 7, the mean privacy scores for African Americans and White participants were 5.54 and 5.40. As a result, there is insufficient evidence to reject the null hypothesis.

Furthermore, the correlation analysis tested the relationship between participants’ mean privacy scores and awareness scores. The null hypothesis of the correlation analysis states there will be an insignificant, weak linear relationship between participant’s privacy and awareness scores. However, the alternative hypothesis states there will be a significant, strong linear relationship between the two variables. The correlation analysis reported a Pearson correlation coefficient of 0.014 (see Table 4). Based on the two-tailed significance value of 0.887, which is greater than 0.05, the null hypothesis was accepted. Both the t-test and correlation analysis revealed African American and White participants to have similar levels of privacy concern about genetic testing. While African Americans possessed a higher awareness of unethical medical testing conducted on African Americans, this had minimal influence on their privacy concerns about genetic testing.

Conclusions, Implications, and Recommendations

Conclusions

This study’s findings conclude non-users of genetic testing services do not possess higher levels of privacy concern, regarding sharing their genetic information with DTC genetic testing companies, than users. Participants selected price and having no desire to know their genetic information as the two most common reasons they hadn’t purchased a genetic test. Privacy issues were the third most selected reason by participants. Other reasons included participants not seeing the benefits in purchasing a genetic test, never making time to purchase one, already seeing family members’ results, and feeling skeptical of the tests’ accuracy. The study also

revealed that while African Americans are more aware of historical instances of unethical medical testing involving African American participants, this is unlikely to result in this group having higher privacy concerns about genetic testing than other ethnic groups. This awareness is also unlikely to deter them from purchasing DTC genetic tests.

Implications

A possible reason the study did not demonstrate a connection between African Americans' awareness of unethical medical testing and privacy concerns about genetic testing is the generation gap between when the events took place and age demographics of the sample. For example, the largest age group of participants included people ages 18 to 24, born between 1994 to 2001. However, the Tuskegee Syphilis Study took place between 1932 to 1972. This study, and other well-known cases of unethical medical testing occurring prior to the 21st century, would've more likely deeply affected the attitudes of people who lived through them. People alive during these studies may have heard about them, or even knew people directly connected to them. While traumatic experiences have a way of being passed down through generations, sometimes the exact opposite occurs. African Americans who experienced, or witnessed the ramifications of these studies, may have been hesitant to have conversations with younger generations about the studies, due to not wanting to relive negative experiences. Even if younger African Americans learned about the studies from family members, the events are already two to three generations removed for many participants.

In addition, individual knowledge of African American history varies amongst African Americans. Excluding the generation gap, some individuals are more likely to seek out and research information about their history than others. Online communities passionate about Black history on social media or Black student organizations on college campuses may possess higher concentrations of younger African Americans knowledgeable about African American history.

Moreover, awareness of the Henrietta Lacks story spread after the publishing of *The Immortal Life of Henrietta Lacks* by Rebecca Skloot in 2000. Prior to the publishing of this biography about Lacks' role in medical research and her family, many Americans outside of the biomedical research community were unaware of her story. In 2017, "The Immortal Life of Henrietta Lacks," a television adaptation of the book, premiered on HBO. While this further increased awareness, there may not be widespread awareness of Lacks' story. The previously mentioned reasons may also explain why participants reported low awareness of the gynecological studies of Dr. J. Marion Sims.

Another possible reason this study did not establish a connection is the sample size. For instance, 103 participants were surveyed, many of whom identify as either African American or White and reside in Kennesaw, GA. If a larger sample size had been collected from participants living in a variety of geographic locations, there may have been more ethnic diversity within the sample. Sampling from more diverse communities would've also increased the proportion of participants who identified as other ethnicities, such as Hispanic American and Asian American groups. This would've allowed for more comparisons of participants' privacy concerns about genetic testing across ethnic groups.

Recommendations

For future studies, the researcher provides the following recommendations. First, the researcher recommends sampling participants living a variety of geographic areas to increase the likelihood of gathering an ethnically-diverse sample. Furthermore, targeting online communities passionate about topics related to the study, such as genealogy and African American history, would increase the likelihood of gathering participants knowledgeable about the topics mentioned. In addition, the researcher recommends identifying locations or online communities where participants of a variety of ages can be targeted. This would increase the diversity of participants' ages within the sample. Lastly, the researcher recommends increasing the sample by 200 to 300 participants to improve the accuracy of the study's results.

Limitations

Limitations of this study included sampling bias, time constraints, and financial constraints. Sampling bias occurred due to a greater proportion of non-users than users of genetic testing being sampled. Of the 103 participants surveyed, 82.5% were non-users and 17.5% were users of genetic testing services. Since the researcher utilized a convenience sampling technique, participants were selected based on their accessibility to the researcher. If more users of genetic testing services had been sampled, the accuracy of the study's results would've improved. In addition, time constraints created another limitation, because the researcher collected responses based on the project's deadlines. The researcher had approximately two months to collect responses, before beginning the data analysis phase. Lastly, financial constraints comprised a limitation, because this limited the researchers' ability to provide incentives to potential participants. Many of the study's participants at Kennesaw State University received academic incentives to participate in the study. If the researcher had provided financial incentives to potential participants outside of the institution, the response rate may have improved.

Tables

Table 1. Privacy Scores of Users vs. Non-Users. T-Test.

T-Test

Group Statistics					
Have you ever purchased a genetic test?		N	Mean	Std. Deviation	Std. Error Mean
Total_Privacy_Score	Yes	18	5.4618	.77717	.18318
	No	85	5.4605	.87596	.09501

Independent Samples Test										
		Levene's Test for Equality of Variances				t-test for Equality of Means				
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Total_Privacy_Score	Equal variances assumed	.905	.344	.006	101	.995	.00131	.22317	-.44140	.44402
	Equal variances not assumed			.006	26.982	.995	.00131	.20635	-.42211	.42473

Table 2. Awareness Scores of African American vs. White Participants. T-Test.

T-Test

Group Statistics					
Which of the following describe your ethnic background? Please check all that apply. - Selected Choice		N	Mean	Std. Deviation	Std. Error Mean
Total_MedTesting_Score	African-American	40	3.1500	1.72620	.27294
	White	49	1.5034	.91571	.13082

Independent Samples Test										
		Levene's Test for Equality of Variances				t-test for Equality of Means				
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Total_MedTesting_Score	Equal variances assumed	24.276	.000	5.762	87	.000	1.64660	.28577	1.07861	2.21459
	Equal variances not assumed			5.440	56.552	.000	1.64660	.30267	1.04041	2.25278

Table 3. Privacy Scores of African American vs. White Participants. T-Test.

T-Test

Group Statistics					
Which of the following describe your ethnic background? Please check all that apply. - Selected Choice					
	N	Mean	Std. Deviation	Std. Error Mean	
Total_Privacy_Score	African-American	40	5.5419	.87171	.13783
	White	49	5.4062	.87294	.12471

Independent Samples Test										
Levene's Test for Equality of Variances					t-test for Equality of Means					
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Total_Privacy_Score	Equal variances assumed	.389	.535	.730	87	.467	.13570	.18590	-.23380	.50520
	Equal variances not assumed			.730	83.515	.467	.13570	.18587	-.23396	.50536

Table 4. Privacy Scores vs. Unethical Medical Testing Scores. Correlation Analysis.

Correlations

Descriptive Statistics			
	Mean	Std. Deviation	N
Total_Privacy_Score	5.4608	.85590	103
Total_MedTesting_Score	2.2104	1.55228	103

Correlations			
		Total_Privacy_Score	Total_MedTesting_Score
Total_Privacy_Score	Pearson Correlation	1	.014
	Sig. (2-tailed)		.887
	N	103	103
Total_MedTesting_Score	Pearson Correlation	.014	1
	Sig. (2-tailed)	.887	
	N	103	103

Figures

Figure 1. Participants by age. Pie chart.

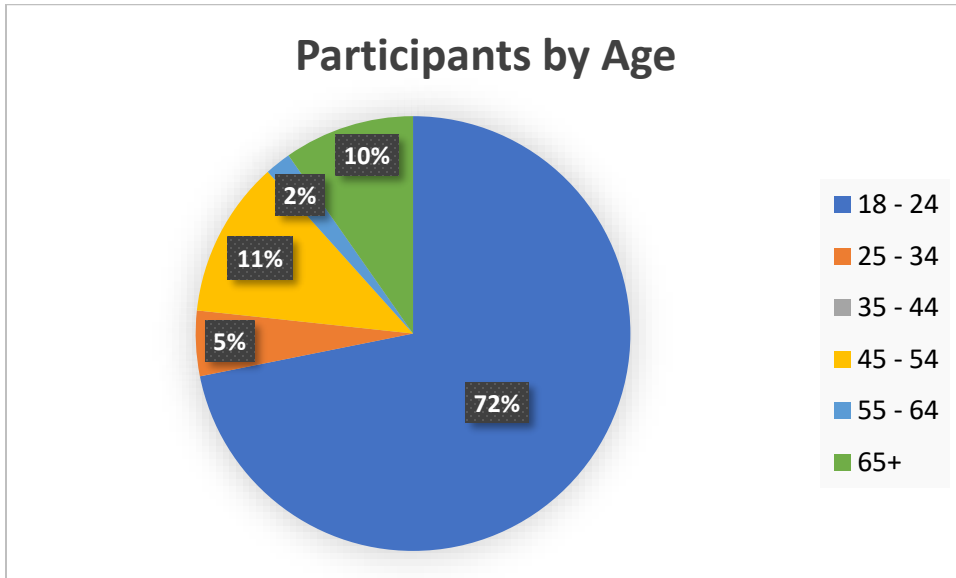


Figure 2. Participants by ethnicity. Pie chart.

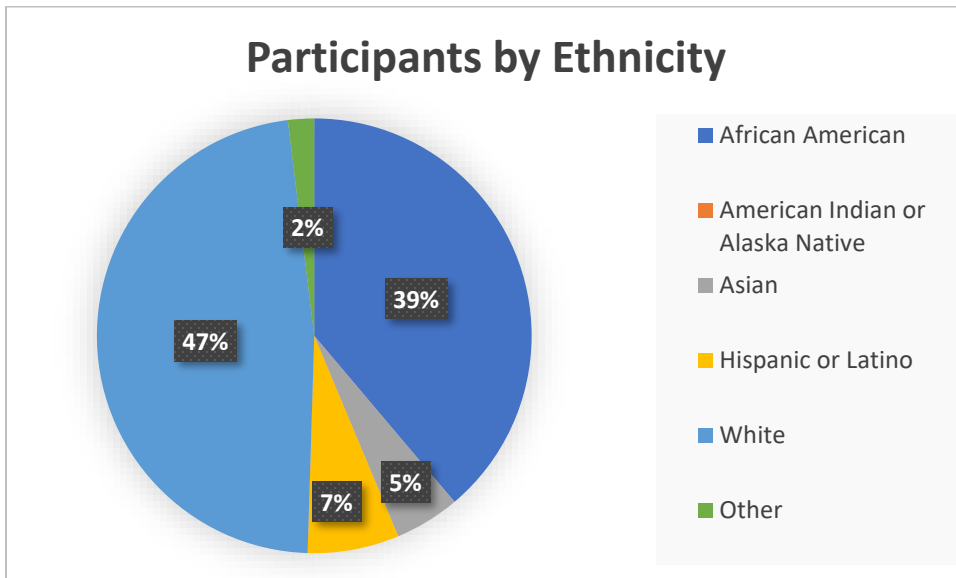


Figure 3. Participants by gender. Pie chart.

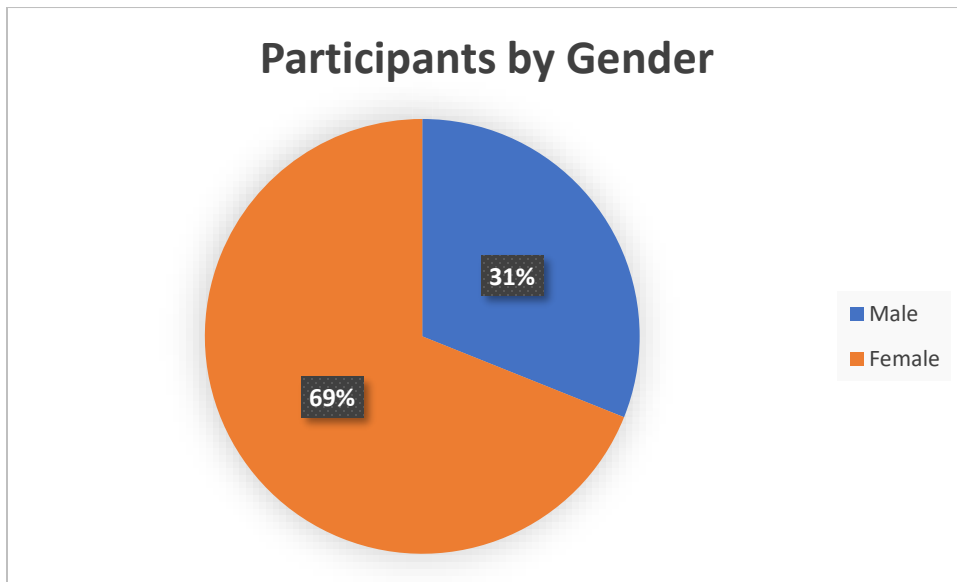


Figure 4. Users vs. non-users. Pie chart.

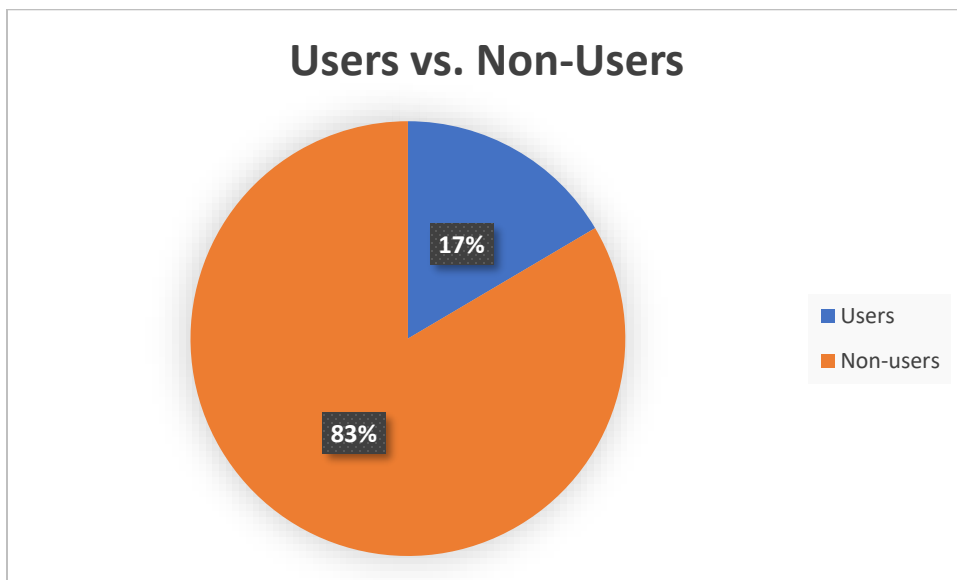


Figure 5. Brand awareness. Bar chart.

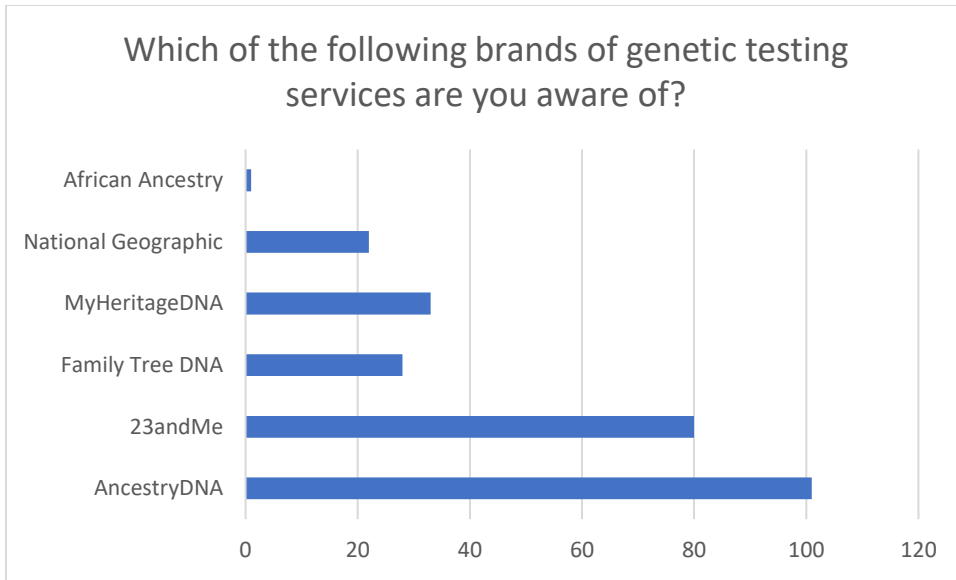


Figure 6. Awareness of HIPAA. Pie Chart.

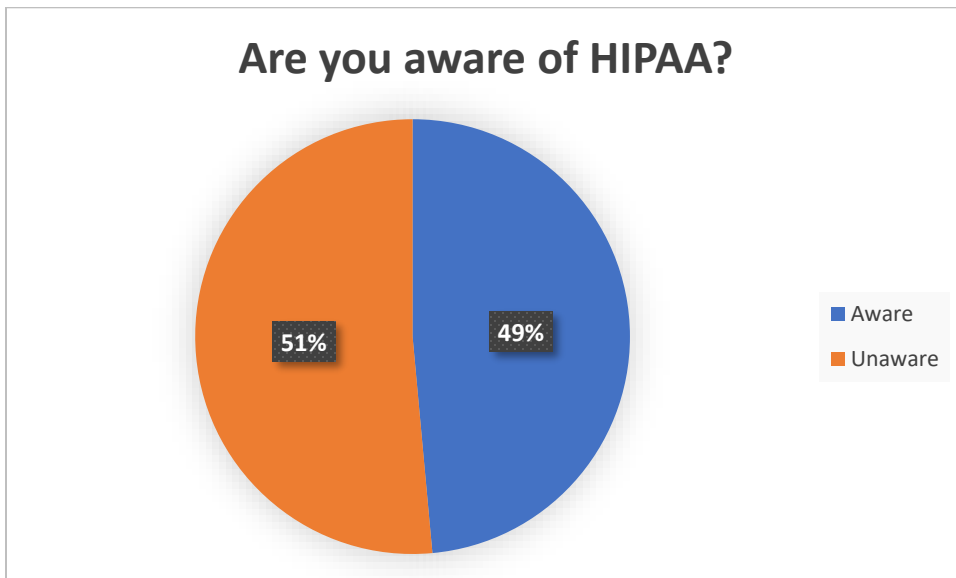


Figure 7. Awareness of GINA. Pie chart.

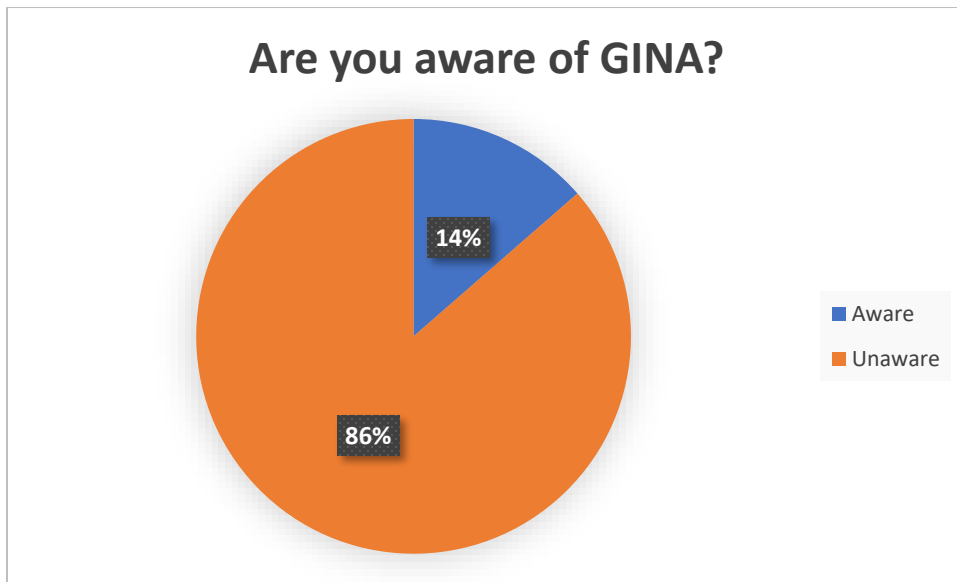
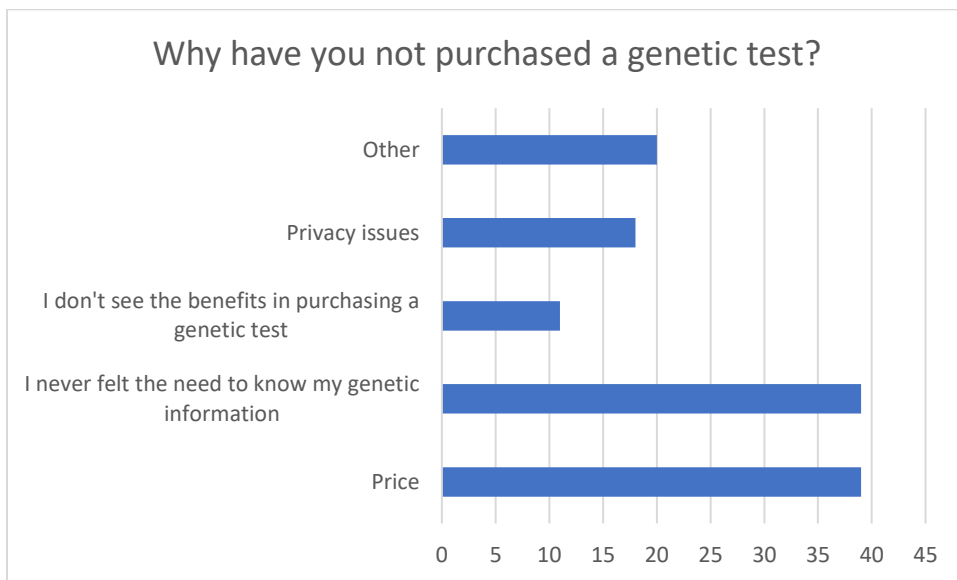


Figure 8. Reasons for not purchasing a genetic test. Bar chart.



Appendices

Appendix A

Questionnaire

Section A

A1. To what extent are you aware of genetic testing services?

- Definitely Unaware
- Somewhat Unaware
- Slightly Unaware
- Slightly Aware
- Somewhat Aware
- Definitely Aware

A2. Which of the following brands of genetic testing services are you aware of? Please check all that apply.

- AncestryDNA
- 23andme
- Family Tree DNA
- MyHeritage DNA
- National Geographic
- Other (please specify):
- None of the above (ends survey)

A3. Have you ever purchased a genetic test?

- Yes
- No

Section B

B1. Which of the following brands have you purchased genetic tests from? Please check all that apply.

- AncestryDNA
- 23andme
- Family Tree DNA
- MyHeritage DNA
- National Geographic
- Other (please specify):
- None of the above

B2. When did you purchase your most recent genetic test?

- Less than 1 year ago
- 1-2 years ago
- 3-4 years ago
- 5 years or more ago

B3. We would like to know what factors you find most important when purchasing a genetic test. Please rank the following factors in order of importance using 1 to represent your first choice and 5 to represent your last choice.

- To learn about my ancestry
- To find new family connections
- To learn my risk of developing certain genetic disorders
- To learn my risk of carrying certain genetic disorders
- Other (please specify):

B4. What information did you learn from your most recent genetic test? Please check all that apply.

- My ancestry
- New family connections
- My risk of developing certain genetic disorders
- My risk of carrying certain genetic disorders
- Other (please specify):

B5. Do you believe that these companies use genetic information ONLY for the above-mentioned purposes?

- Strongly Disagree
- Slightly Disagree
- Somewhat Disagree
- Neither Agree or Disagree
- Slightly Agree
- Somewhat Agree
- Strongly Agree

B6. To what extent were you satisfied with this genetic testing service?

- Definitely Dissatisfied
- Slightly Dissatisfied
- Somewhat Dissatisfied
- Neither Satisfied or Dissatisfied
- Slightly Satisfied
- Somewhat Satisfied
- Definitely Satisfied

B7. How carefully did you read the privacy policy before purchasing this genetic testing service? (Custom scale: 1= Very carefully, 7 = Not at all carefully, Accepted without reading)

B8. To what extent did you understand the privacy policy before purchasing this genetic testing service? (1 = Did not understand at all, 7 = Completely Understood)

Section C

C1. To what extent do you agree with the following statements about how genetic testing companies should keep you informed about the genetic information they have about you? (1 = Strongly Disagree, 7 = Strongly Agree)

- Genetic testing companies should disclose how the data will be collected, processed, and used.
- Genetic testing companies should have a clear and concise online privacy policy.
- It is a priority for me to be aware and knowledgeable of how my genetic information will be used.

C2. To what extent do you agree with the following statements about how genetic testing companies should use your genetic information? (1 = Strongly Disagree, 7 = Strongly Agree)

- Genetic testing companies should not use my genetic information for any purposes other than those authorized by me.
- Genetic testing companies should never sell my genetic information, stored in their computer database, to third parties.
- Genetic testing companies should not share my genetic information for any purposes other than those authorized by me.

C3. To what extent do you agree with the following statement regarding how genetic testing companies handle genetic information? (1 = Strongly Disagree, 7 = Strongly Agree)

- Compared to others, I am more sensitive about how genetic testing companies handle my genetic information.
- All things considered, genetic testing would cause serious privacy problems.

C4. To what extent do you agree with the following statements regarding the risks associated with sharing genetic information. (1 = Strongly Disagree, 7 = Strongly Agree)

- In general, it would be risky to give genetic information to online companies.
- There would be too much uncertainty involved with giving genetic information to genetic testing companies.
- I would feel safe giving my genetic information to online companies.

C5. To what extent do you agree with the following statements regarding the trustworthiness of genetic testing companies. (1 = Strongly Disagree, 7 = Strongly Agree)

- Genetic testing companies would be trustworthy in handling my genetic information.
- Genetic testing companies would be trustworthy in handling the genetic information of other people.
- I trust that genetic testing companies would keep my best interests in mind when dealing with my genetic information.
- I trust that genetic testing companies would keep the best interests of other people in mind when dealing with their genetic information
- Genetic testing companies are always honest with customers when it comes to using their genetic information

C6. To what extent are you aware of the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule?

- Definitely Unaware
- Somewhat Unaware
- Slightly Unaware

- Slightly Aware
- Somewhat Aware
- Definitely Aware

C7. To what extent are you aware of the Genetic Information Nondiscrimination Act (GINA)?

- Definitely Unaware
- Somewhat Unaware
- Slightly Unaware
- Slightly Aware
- Somewhat Aware
- Definitely Aware

C8. To what extent are you aware of the role of Henrietta Lacks in medical research?

- Definitely Unaware
- Somewhat Unaware
- Slightly Unaware
- Slightly Aware
- Somewhat Aware
- Definitely Aware

C9. To what extent are you aware of the Tuskegee Syphilis Study?

- Definitely Unaware
- Somewhat Unaware
- Slightly Unaware
- Slightly Aware
- Somewhat Aware
- Definitely Aware

C10. To what extent are you aware of the gynecological studies of Dr. J. Marion Sims?

- Definitely Unaware
- Somewhat Unaware
- Slightly Unaware
- Slightly Aware
- Somewhat Aware
- Definitely Aware

Section D

D1. What is your age?

- 18 to 24 years
- 25 to 34 years
- 35 to 44 years
- 45 to 54 years
- 55 to 64 years
- 65 or older

D2. What is your gender?

- Male
- Female
- Other

D3. Which of the following describe your ethnic background? Check all that apply.

- African-American
- American Indian or Alaska Native
- Asian
- Hispanic or Latino
- White
- Other (please specify):

Section E

Thank you for completing this survey! This survey's title is "Attitudes Toward Genetic Testing in the United States."

In this section, the researcher has included additional information about the legislations, historical figures, and events mentioned in the survey.

- According to the U.S. Department of Health & Human Services, the **Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule** "establishes national standards to protect individuals' medical records and other personal health information."
- According to the U.S. Department of Health & Human Services, the **Genetic Information Nondiscrimination Act (GINA)** "protects individuals against discrimination based on their genetic information in health coverage and in employment."
- **Henrietta Lacks** (1920 – 1951) was an African-American woman whose cancer cells were the source of the HeLa cell line, the first immortalized cell line in medical research. Her cells were essential to scientific advancements such as the polio vaccine, cloning, *in vitro* fertilization, and gene mapping. There was no informed consent obtained from Henrietta Lacks.
- The **Tuskegee Syphilis Study**, officially named the Tuskegee Study of Untreated Syphilis in the Negro Male, was a medical research study conducted from 1932 to 1972 by the U.S. Public Health Service (PHS). The purpose of the study was to measure the natural progression of untreated syphilis in African-American men in Macon County, Alabama. The sample population included 201 uninfected patients and 399 infected patients. Subjects were not informed of the purpose of the study, or of their condition.
- From 1845 to 1849, **Dr. J. Marion Sims** (1813 – 1883), known as the "father of modern gynecology", performed surgical experiments on enslaved women in the southern United States. The experiments resulted in the development of a cure for the vesicovaginal fistula. Sims did not administer anesthesia to the subjects and he did not seek informed consent.

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