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## Gifted Genes: An Investigation of College Student Perceptions of Direct-To-Consumer Genetic Kits

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**Gifted Genes:**  
**An Investigation of College Student Perceptions of**  
**Direct-To-Consumer Genetic Kits**

A project submitted in partial fulfillment of the requirements for the Minor in Honors  
Interdisciplinary Studies.

by

Kate Amos

June 13, 2022

Honors College  
Western Washington University

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## **ABSTRACT**

This study is based on a classroom-use only pilot survey of college student perceptions of direct-to-consumer genetic tests. These tests can provide information about an individual's genealogy and ancestry, as well as their medical genetic profile and genetic risk factors. The survey was designed for ease-of-use using Qualtrics (Qualtrics 2022) and distributed using anonymous links and a QR code. A total of forty complete responses were recorded during the twenty-two days the survey remained open, which were analyzed using descriptive statistics. Respondents were mainly in their late teens to early twenties, just over half identified as female, and almost three-quarters identified as white. Most students reported receiving the tests as gifts and using them to learn about genealogy and ancestry or for fun. A large portion also responded that they had previously thought about genetic privacy. Ultimately, the trends revealed by the survey created a wide variety of pathways for future research to gain more insight into how college students approach using direct-to-consumer genetic tests.

## INTRODUCTION

This research examines college student perceptions of direct-to-consumer genetic tests. This is not an area that has seen much research, as much of what currently exists in the literature is focused on student interest in the use of these tests in a classroom setting and whether colleges are providing the information needed for students to understand how genetic testing works and can be used. Additionally, the existing research also examines attitudes towards genetic testing and its use in medicine. However, there is plenty of research into the perceptions and concerns of other populations, which provided a starting point for this research.

College students are an interesting population to research, as they seem to exist in a liminal space between childhood and entering the workforce as adults. They are no longer children but can also still be dependent on their parents or other authority figures in their lives, so perhaps not as fully self-sufficient as they will become in the future. This can mean that college students possess a unique perspective on life and the world and may provide interesting insights into research questions. In the case of this study, especially as it is being conducted at an undergraduate institution, college students are a population that I have spent the last few years surrounded by, and I was fascinated to see what I would discover about their perceptions of direct-to-consumer genetic tests.

The research in the study is based on a survey, as that allows for the collection of responses on a broader variety of topics and from a larger number of individuals. The survey was designed to be easy for people to take to hopefully increase the total number of respondents. It was distributed via anonymous links and QR codes to students at Western Washington University. Once data was collected, it would be downloaded to a secure computer for descriptive statistical analysis.

Specifically, this research asks the following questions: how do college students obtain these tests? How are they used? Do students understand what they are giving the direct-to-consumer genetic test companies in exchange for their test results?

## **LITERATURE REVIEW**

A direct-to-consumer genetic test (DTC-GT) is an at-home kit that an individual can purchase for the purpose of getting their DNA analyzed for markers that can be used to indicate geographical ancestry, find relatives, or gain insight into their overall medical genetic profile and any specific genetic risk markers that they may possess (Arnold and Bonython 2019; Horton et al. 2019). The cost of a DTC-GT can vary depending on the company it is purchased from, as well as the range of services being offered. A basic ancestry test from leading companies like 23andMe or AncestryDNA costs around \$100, with added benefits like health reports from 23andMe or extended access to resources from AncestryDNA doubling the cost to \$200 (23andMe n.d.; “AncestryDNA® | DNA Tests for Ethnicity & Genealogy DNA Test” n.d.). Currently, the only company with FDA approval to generate health reports based on a genetic profile is 23andMe. The tests kits are relatively simple to use, as all that is required from the user is to send in a sample of their saliva for testing, with the collection tube and return box being provided by the company (“Collecting a Saliva Sample” n.d.; “Getting Started With the 23andMe DNA Test Kit” n.d.).

After the spit-filled tube has been sent for analysis, ownership passes to the company providing the service, and they can do what they wish with the data, so long as it does not violate the company’s privacy policy or break any laws (King 2019). In the United States, the only law regulating DTC-GT companies is the Genetic Information Non-Discrimination Act (GINA),

which prevents discrimination by employers or health insurance companies on the basis of genetic test results, but otherwise leaves companies free to act as they please (King 2019). As companies process samples, they are able to build up a database full of genetic information from individuals around the world for use in their own analysis, or that can be shared with other companies for pharmaceutical or biomedical research purposes; as one paper put it, this is data that a fully informed individual would not willingly provide to any insurance company, pharmaceutical company, or any other similar organization (Arnold and Bonython 2019).

Companies are able to continue to amass large amounts of incredibly personal data due to a lack of regulation outside of GINA, or other regulations that focus on whether a company is providing reliable and accurate results that could be used in a clinical setting, like a physician's office (Gollust et al. 2017). Concerns have arisen surrounding the extent to which consumers understand what they are agreeing to when they send a sample in for analysis, as the terms and conditions can be written at a college reading level, which may be beyond an individual's ability to understand. The United States National Library of Medicine recommends that health-based consumer information should be written at a middle grade reading comprehension level (Hendricks-Sturup and Lu 2019), to ensure that they are accessible to those intending to use the product. Beyond the sometimes difficulty in comprehension, it has been noted in the last several years that the terms and conditions set by DTC-GT companies do not allow for an individual to revoke their consent at any time after it is given (Gollust et al. 2017), even if they are concerned by the way a company may be using their private information.

One of the most significant concerns that has emerged is the use of DTC-GT generated databases by law enforcement, as in the case of the Golden State Killer, who was caught decades after the crimes were committed through the use of familial DNA matches generated by a public-

access genealogy database (Hazel et al. 2021). Without these companies, this case may never have been solved, but it also revealed new questions regarding privacy and access to these databases. No clear regulations exist for law enforcement, and while significant good can come from the use of the genealogical databases generated by DTC-GT kits, research has also shown that there are concerns about unfettered access by law enforcement, especially when it comes to overly-broad warrants, instead of using a database to confirm the identity of a potential suspect (Hazel et al. 2021), and suggestions have been made that access to these databases should be restricted to protect the civil liberties of those whose information they contain (Arnold and Bonython 2019).

For companies to build their databases, they need consumers to purchase and use their tests, but the extent to which the consumer receives helpful information is limited by the size of a company's database. To generate information about a person's geographical ancestry, there need to be other individuals with that shared ancestry in the database for comparison (Hazel et al. 2021). A longitudinal study of DTC-GT users in the U.S. found that the majority were white (Gollust et al. 2017), which indicates that different populations are likely to have varying levels of detail in their results due to a potential lack of data. It may be frustrating for those individuals from poorly sampled populations to receive less detailed results than those for individuals from widely sampled populations, despite paying for the same services.

However, different companies will have different makeups of their databanks. An analysis of the r/AncestryDNA and r/23andme subreddits found that a higher portion (75.5%) of the AncestryDNA ethnic regions are "for people of European heritage" (Yin et al. 2020) compared to the 30.4% of the regions used by 23andMe (Yin et al. 2020). The division of the world population into ethnic regions ties into the idea that geographic ancestry, the geographical



region in which an individual's family lived decades before, has been conflated with the idea of ethnicity, which is a cultural idea involving how lived experiences in an environment shape an individual's identity. For some, the lived experiences were far more significant than geographical ancestry (Hazel et al. 2021), though that is something that truly depends on the individual.

Aside from geographical ancestry, DTC-GT companies also serve to connect individuals to those who share their DNA. On one level, this can allow someone to find new family when they knew nothing, but it also means that someone taking a DTC-GT is offering up not only their own DNA, but also that of any relative sharing a genetic connection, who may not have made the decision to do that themselves (Darroch and Smith 2021). The more closely related individuals are, the more DNA that is shared. For some, sharing their genetic profile with the world means risking the discovery of previously unknown relatives or uncovering buried family secrets like a sibling actually being a parent, or a parent having no genetic connection to a child (Hazel et al. 2021).

The development and now widespread enough use of DTC-GT means that even people who did not share their genetic matches or any identifying details could be found if a searcher is willing to put in the effort to narrow down a family tree (Darroch and Smith 2021). The potential ease with which someone could be identified via usage of DTC-GT kits means that there is no way for previously private or concealed information to stay that way. Closed adoptions or private sperm donations can all be uncovered if close enough relatives chose to share their genetic profile in the hopes of finding new family members (Darroch and Smith 2021).

Contrary to what some may believe, and what may be advertised, only one DTC-GT company has received FDA approval to offer medical genetic profile creation or identification of genetic risk factors, 23andMe, and only since 2017 (Gollust et al. 2017). There are third-party

services that offer analysis of raw genetic data for health risk markers, but those sites may not offer sufficient informed consent, analysis is not necessarily supervised by medical professionals, and results may not be accurate enough for clinical use (Yin et al. 2020), none of which sounds reassuring for the generation of accurate results.

When genetic risk factors for disease are being determined, it is a measurement of whether a specific variant of a gene that has been linked with a given disease is pathogenic or benign—will it cause disease or not. In order for a variant to be defined as pathogenic, researchers must be able to observe how the variant behaves in a large, diverse population to see what other factors may result in pathogenic behavior (Popejoy et al. 2018). If the data is based in a single population, say one of primarily European descent, then the results that hold true for one population may not apply to another. In the Popejoy paper, there is discussion of a genetic variant that was initially identified as pathogenic in people of European descent that was ultimately found to be benign in African American populations, but not before African American individuals were subjected to invasive procedures that were unnecessary without a pathogenic variant.

Additionally, without widespread testing, the odds of encountering a variant with unknown affects increases for individuals of non-European descent, simply on the basis of a lack of data (Popejoy et al. 2018). The limited scope of analysis offered by DTC-GT companies can also lead to false negative results, as not all variants are tested for, and the most common pathogenic variants change based on the population being studied (Horton et al. 2019). When a patient sees a geneticist or a genetic counselor, the context that comes from knowing a person's medical history, insofar as it is possible to know, allows for more targeted testing that will look for variants using that contextual understanding (Horton et al. 2019).

In a 2014 paper examining college students' interest in using DTC-GTs in a classroom setting, it was found that 96% of the respondents either strongly agreed or agreed that they would consult a physician for help interpreting their test results (Austriaco 2014). Additionally, only 46% of the students surveyed strongly agreed or agreed that they believed their physicians would have the knowledge necessary to interpret DTC-GT results (Austriaco 2014). Other research has shown that genetic counselors have their own concerns about providing service to consumers of DTC-GTs. One survey found that genetic counselors can have concerns about the accuracy about the results provided by a DTC-GT, as well as that their own knowledge, or lack thereof, of how DTC-GTs work would negatively impact their ability to provide service to patients who had used a DTC-GT (Hsieh et al. 2021). Overall, the majority of the genetic counselors surveyed believe that the DTC-GT companies should be providing access to genetic counselors as part of their service, rather than leaving their customers to seek genetic counseling service separately (Hsieh et al. 2021).

The literature focused on college students was limited, mainly focused on the use of DTC-GTs in a classroom setting or around the knowledge and awareness of college students regarding genetic testing. One survey, referenced in the previous paragraph, was administered to students in an introductory biology class at Providence College, where the majority of the class were either majoring in biology, chemistry, or biochemistry (Austriaco 2014). At the time the survey was administered, it was found that student knowledge of DTC-GTs was limited, but there was interest in using the tests in a classroom setting (Austriaco 2014). For some students, the chance to use a DTC-GT at a reduced cost was an influencing factor, but students still had concerns about the reliability of the tests, the confidentiality of their results, and their ability, or that of a physician, to interpret the results (Austriaco 2014).

Some of the research based on college students took place in other parts of the world, which means it may not entirely reflect college students in the United States. However, it generally found that college students' opinions towards and acceptance of genetic testing tended to be based in part on their overall understanding of how genetic testing works (Alsafar et al. 2021; Olwi, Merdad, and Ramadan 2016). Surveying students at King Abdulaziz University in Saudi Arabia found that the possession of general genetics knowledge did not fully correlate with a detailed understanding of genetics and genetic testing, and that the attitudes towards genetic testing were more likely to be influenced by the students' environment and their culture than by their degree of knowledge (Olwi, Merdad, and Ramadan 2016).

The literature did not seem to contain any studies examining college students' experience with or general perceptions of DTC-GTs. Instead, the literature focused on college students was more likely to examine their attitudes towards using DTC-GTs in a classroom setting, specifically the tests that look for genetic risk factors or generate a medical genetic profile. Any data looking at attitudes and experiences seemed to be focused on older populations, simply based on the populations most likely to have purchased and used the tests. As mentioned previously, those populations tend to be older, more often female than male, and mostly college educated Caucasian individuals (Yin et al. 2020).

## **METHODS AND ANALYSIS**

This study is based on the surveying of enrolled college students who have used a DTC-GT. The survey was a pilot survey, intended to generate preliminary data that can be used to design the direction of future research. As this research is for classroom use only, it did not require IRB

approval. The anonymous nature of the survey meant that identifying information was not collected.

The questions for the survey were created by examining the types of questions asked in the literature of larger formal studies and shaped by what I was interested in examining. The questions were all designed to be simple multiple-choice questions (see appendix A). The survey was restricted to twenty questions for a to ensure that students would complete it. The draft survey was shared with my faculty advisor and a few individuals that fit the inclusion criteria to ensure that all the questions were clear and that the survey was easy to take. The sample population for this experiment was enrolled college students at Western Washington University (WWU) that are at least 18 years old and have used a DTC-GT. The survey was advertised via email to current members of Western Washington University's Honors College, via the WWU sub-Reddit, via my advisor's Twitter page, and via my personal Instagram page. The survey was shared using anonymous links and a QR code. The survey was administered via Qualtrics (Qualtrics 2022). The survey remained open for twenty-two days and forty individuals completed it. Survey data was downloaded and saved on a password protected computer for analysis. Given the small number of respondents, the survey data was analyzed using descriptive statistics.

For analytical purposes, some of the "Other" text answers were recategorized. For the respondent's area of study, majors were grouped in with the correct area, and any answer with more than one response only used the first program indicated. The answer "interdisciplinary" was left as "Other not listed", since there was not enough information to recategorize it. The "Environmental Science" answer was also left as "Other not listed" as it can span multiple of the listed categories. Future research would need to address this. For "other" answers regarding how

the kit was obtained, they were either a variation on a parent purchasing it, or that it was gifted to a parent that did not want to use it. These answers were all recategorized as “It was a gift”.

Additionally, the final question was a text response where respondents could share about their experience if they desired. These answers were manually sorted by the themes they contained into categories for analytical purposes. Two responses were deleted, which will be discussed more in the next section.

## **FINDINGS**

The majority (77.5%) of respondents were in the 18-22 age range, 59.5% identify as female, 73.8% identify as white, only 25% identify as having a disability or chronic illness, and only 12.5% identify as being adopted (Table 1). There was far more variation within the areas of study of the respondents, with the highest percentage of respondents (27.5%) listing social, behavioral, and economic sciences as their primary area of study (Table 2).

Most individuals reported that they received their DTC-GT as a gift (67.5%) as seen in Table 3. The tests provided by 23andMe were used most often (55.0%), followed by AncestryDNA (37.5%), and two people (5.0%) responded that they used a different test, both from the brand MyHeritage. One person could not remember what brand they used. There was a wide range of ages at which individuals used the tests, the youngest being thirteen years old, while the largest number of respondents for a single age was 20% at age nineteen (Table 4). The most common purposes for using the test were to learn about genealogy and ancestry (88.1%) or for fun (66.7%), shown in Table 5. One person reported that the reason they used the test was familial pressure.

Further analysis was done to see what trends in the purpose of test used existed for individuals identifying as having a disability or chronic illness or identifying as being adopted. Of the ten individuals that reported having a disability or chronic illness, 100% also reported that the purpose for using the test was to learn about their genealogy and ancestry and 70% reported that they did it for fun (Table 6). The five individuals that reported being adopted gave learning about their genealogy and ancestry (80%) and finding family members (80%) as two of the top purposes for using the test (Table 7).

Respondents were also asked about their satisfaction regarding their experience based on whether they used the DTC-GT to learn about their genealogy and ancestry, to learn about their medical genetic profile, or to learn about their genetic risk factors. Most individuals who used the test for genealogy and ancestry purposes responded that they were satisfied with what they learned (65.0%), though some were unsure (17.5%). The satisfaction responses for learning about their medical genetic profile or genetic risk factors did not have as clear of a majority. For those who learned about their medical genetic profile, only 32.5% were satisfied with what they learned and 17.5% were dissatisfied. The trend was similar for those who learned about their genetic risk factors, with 27.5% reporting satisfaction and 22.5% responding that they were not satisfied with what they learned

Examining whether respondents read and understood the terms and conditions for the test they used revealed that only 35% reported reading the terms and conditions, 52.5% did not read the terms and conditions, and 12.5% did not know if they read the terms and conditions. When it came to understanding the terms and conditions, 27.5% responded “yes”, 57.5% did not understand them, and 15% did not know if they understood the terms and conditions. When looking at the portion of respondents that answered yes to both questions, only 25% did so, and

one person responded that they did not know if they read the terms and conditions, but that they did understand the terms and conditions, something that will be discussed later in this paper.

Additionally, when asked whether they shared their genetic profile with the company that made the test they used, 37.5% of respondents answered “I don’t know”, 17.5% answered “no”, and 45% answered “yes”. When asked if they shared their genetic profiles with other companies for analysis, 20% responded in the affirmative, 40% responded in the negative, and 40% were unsure. Interestingly, 82.5% of respondents reported that they had previously thought about privacy regarding the sharing of their genetic information, and 17.5% reported that they had not thought about it.

When asked whether they would recommend other people use the test, respondents were split between the answers. The majority (47.5%) reported that they would recommend the test to others, 35.0% said they would maybe recommend the test, 10% said they would not recommend the test, and 7.5% of respondents were unsure if they would recommend the test to others.

The last question of the survey was a free response asking people if they had anything else they wanted to share. These answers varied, and some contained multiple themes. Nearly half (45%) of respondents chose to not share any additional information. The most frequent theme was that the respondents had fun with their experiences (15%), that the tests do not provide enough information (12.5%), and that the companies are not well regulated and do not do a sufficient job of explaining how they use the DNA (12.5%).

## **DISCUSSION**

Many of the respondents were in the 18-22 age range, which is consistent with the expected age range for undergraduate college students in the United States (“College Enrollment & Student



Demographic Statistics” n.d.). Nearly 60% of the respondents identified as female, which parallels the 57% of the Western Washington University student body that identifies as female (“Quick Facts | Admissions | Western Washington University” n.d.). WWU is also a predominantly white institution, which is consistent with most of the individuals that completed the survey identifying as white (“Quick Facts | Admissions | Western Washington University” n.d.). Only 25% of the respondents identified as having a disability or chronic illness and only 12.5% identified as having been adopted. The small percentages mean that no rigorous statistical analysis could be conducted with these data, so instead it was just examined for any changes from the overall trend, with no consideration of whether the changes were statistically significant.

The largest number of individuals in a single area of study was 27.5% of respondents reporting studying Social, Behavioral, and Economic Sciences. Biological Sciences and Humanities took spots two and three, with 22.5% and 20% of respondents, respectively, in each category. Again, as per the WWU Admissions Office, the College of Humanities and Social Sciences is the largest on campus, issuing 40% of all degrees, followed by the College of Science and Engineering (18%) and College of Business and Economics (17%). The area of study responses did require some recategorizing, as some individuals listed their specific major and others listed multiple programs. When multiple programs were listed, the first program was selected. Additionally, there were two responses that could not easily be recategorized into a single area of study due to the interdisciplinary nature of “Environmental Science” and the non-specificity of “Interdisciplinary”. Future studies would need to address these issues, perhaps by creating more categories for people to choose from and adding instruction to select their primary area of study if they have more than one.

The most common means of obtaining a DTC-GT was “as a gift” with 67.5% of respondents reporting they obtained their tests in this manner. There were four answers that were recategorized as gifts, including parents purchasing the tests for their children to use, or a parent regifting a test to their child because the parent did not want to use it. The overall trend of respondents receiving the DTC-GT as a gift aligns with the hypothesis that college students would be more likely to receive these tests as gifts rather than purchasing the tests themselves. It would be interesting to use future research to determine whether students were more likely to request a DTC-GT as a gift or for it to be a surprise, and whether there is a cost component that makes it more likely that a student receives a DTC-GT as a gift rather than purchasing it themselves.

Some of the recategorizing of the responses for how the tests were obtained is likely due to differing ideas of what it means to receive something as a gift. Three out of the four answers that were grouped in with having received the DTC-GT as a gift referenced having a parent purchase the test for their child to use. While that clearly does not fit with having purchased a DTC-GT yourself, it also may not be considered a gift. When designing the survey, I was operating from the definition of gift that classified it as an item given to an individual by another person, frequently within the context of a birthday, holiday, or other special occasion. However, that definition does not necessarily leave space for the moments where a parent purchases something for a child to use, as that does not necessarily fall into a definition of a gift. This question may have been better served by adding a definition of a gift or by changing the phrasing of answers to provide multiple options for how someone could receive a DTC-GT from another individual, such as “my parent(s) bought it for me”.

Tests from 23andMe were used most often (55%), followed by AncestryDNA (37.5%). This is unsurprising given that these are some of the most well-known brands. Additionally, 23andMe is the only company certified by the FDA for use in medical genetic testing, whether to create an overall medical genetic profile or to determine risk factors for a specific condition, which means that anyone wanting to use a DTC-GT to better understand their health would need to use a test from 23andMe or look to third-party providers to analyze a genetic profile obtained from using a DTC-GT. The ages at which survey participants fits, at least partially, with the high percentage of tests received as gifts. The youngest point at which someone used a DTC-GT was age thirteen, and the largest response for a single age was 20% of respondents using a DTC-GT at age nineteen. Of the total number of respondents, 32.5% of them reported using a DTC-GT before the age of eighteen, which is not entirely surprising if nearly 70% of the respondents received the DTC-GT as a gift.

Most often, the DTC-GTs were used for an individual to learn about their genealogy and ancestry (88.1%) or just for fun (66.7%). However, one person did report that the reason they used a DTC-GT was due to familial pressure, which would have been an interesting response to explore further with more detailed questions or a post-survey interview. Fewer individuals reported that one of their purposes for using the DTC-GT was to learn about their medical genetic profile (35.7%), to learn about their genetic risk factors (23.8%), or to find family members (16.7%). It is not entirely surprising that the number of people who reported that they wanted to learn about health-related topics is lower, especially since only one DTC-GT company offers those services, and the cost almost doubles when health reports are added to basic geographical ancestry analysis.

Though the sample size was too small for statistical analysis, I did still examine the trends in DTC-GT use for individuals who indicated that they either had a disability or chronic illness or were adopted to see if there were any differences from the overall trends. The top purposes for use of DTC-GTs for individuals with disabilities or chronic illnesses was to learn about their genealogy and ancestry (100%), followed by using the DTC-GT for fun (70%). Learning about their medical genetic profile or genetic risk factors were less common uses, at 50% and 40% of respondents respectively. These percentages are higher than in the overall reports, but the smaller sample size may be an influencing factor to make these numbers seem higher than what they might be in larger populations.

My initial hypothesis was that having a disability or chronic illness would increase the likelihood that an individual would choose to use a DTC-GT that provides a medical report in addition to the genealogy and ancestry report. However, not all disabilities have a genetic basis, so those individuals may not be interested in receiving a report about their medical genetic profile or genetic risk factors. The same idea may hold true for those with chronic illnesses—depending on the individual and their condition, they may already know everything they consider significant in terms of their health. Future research may be well served by separating these identities in the demographics section of a survey and asking follow-up questions in an interview to identify any factors that influenced the individual's decision regarding purchasing a DTC-GT that could also provide a health report.

Individuals that reported they were adopted had an interesting trend in their purposes for using a DTC-GT. Using a test to learn about genealogy and ancestry or to find family members were both selected by 80% of respondents. Using a test for learning about their medical genetic profile or learning about genetic risk factors were both selected by 60% of respondents. Like

with the trends observed in individuals with a disability or chronic illness, the sample size was too small for rigorous statistical analysis, so it is unclear whether these trends can truly be applied to a larger population. The observed trends are understandable under a hypothesis that adopted individuals are less likely to know, genetically speaking, where their roots lie and to whom they may be connected. Additionally, a potential increase in the desire to use a DTC-GT to learn about their medical genetic profile or genetic risk factors could be linked to a decreased likelihood that these individuals would be in possession of any medical history from their genetic family. Not knowing genetic family medical history can mean that an individual does not have the opportunity to make changes to their lifestyle or their approach to medical care that could reduce disease risk or help quickly catch any developing conditions or diseases.

When asking individuals about their levels of satisfaction with three different purposes for using a DTC-GT, the percentage of individuals indicating they were satisfied by what they learned decreased based on the purpose for test use. Those who chose to learn about their genealogy and ancestry were most likely to be satisfied, with 65% answering yes. One individual did note that they wished the results had been a little more specific, which could be connected back to the idea that these results are generated based on company-cultivated databases filled with the genetic profiles of individuals who had previously used the service. If someone does not match with many of the trends observed in tested populations, then their results would be less specific due to a lack of data.

In individuals that chose to learn about their medical genetic profile or genetic risk factors, the satisfaction levels were far more varied. Only 32.5% of individuals reported being satisfied with what they learned from their medical genetic profile and 17.5% were dissatisfied. For those learning about their genetic risk factors, the satisfaction versus dissatisfaction levels

were even closer, at 27.5% and 22.5% of the responses respectively. There were a larger percentage of both questions that were comprised of the “I don’t know”, “I prefer not to answer”, and “Other” responses, which may be partially due to the design of the question. There was no clear way for individuals to indicate that they did not use the DTC-GT for these purposes, which means people may have all chosen to answer in different manners, confounding the data.

Future surveys would need to address this, whether by skip questions based on the indicated use of the DTC-GT, or by offering a clear option for individuals who did not use the test for a given purpose. Additionally, the question itself should include a definition of what satisfaction means for the survey purposes to ensure that respondents all have the same understanding of what the question is asking before they answer. It may also be useful to assess whether the DTC-GT services matched individuals’ expectations, since satisfaction can be based on whether an individual was pleased with their results and therefore would not provide information on whether the tests worked as advertised.

The respondents were asked whether they read the terms and conditions for the DTC-GT that they used, as well as whether they understood what they read. There were fourteen individuals (35%) that reported reading the terms and conditions, while the remaining 65% either had not read, or were not sure if they had read the terms and conditions. When asked if they understood what they had read, eleven respondents (27.5%) answered “yes” and the remaining 72.5% were not sure if they understood or did not understand the terms and conditions.

What was most interesting was that only 25% of respondents had answered yes to both questions, which is lower than the total percentage of affirmative answers for understanding the terms and conditions. When examining the data further, it was determined that one individual reported “I don’t know” for reading the terms and conditions, but answered that, yes, they

understood them. I am unsure if that was an accidental yes response, as it does not seem possible to be unsure if you read the terms and conditions but confident that you understood them. The terms and conditions for DTC-GTs are frequently written at a college reading level, and though the population for the survey was college students, I do question whether the students that reported understanding the terms and conditions actually did or if they responded in the affirmative to make themselves seem more impressive.

For a company to generate a set of results from a DTC-GT sample, individuals must share their raw profile with that company. However, when asked whether they shared their genetic profile with the company that made their test, only 45% of respondents, eighteen individuals, responded that they shared their profile. Of the remaining twenty-two individuals, fifteen responded that they did not know (37.5%), which indicates that the question may not have been entirely clear and may not have been necessary for the overall survey. When asked if they shared their genetic profile with companies other than the company that made the test they used, 20% of respondents replied that they had, but the other 80% was evenly split, 40% and 40%, between “no” and “I don’t know”. This question could have been improved by adding an additional definition or explanation of what the question was asking, or by rephrasing it to ask if the respondents had chosen to share their genetic profiles with a third-party company for further analysis.

In addition to asking whether people had chosen to share their genetic profiles, I also asked whether they had ever thought about genetic privacy before taking this survey. Surprisingly, more than 80%, thirty-three individuals, replied that they had previously thought about privacy and the remaining seven individuals had not. This result was somewhat unexpected as I had believed that there would be a more even split between the yes and no

answers. It made me wonder what people were thinking about when they considered genetic privacy, and whether it influenced their decision to use a DTC-GT in any way. Further examination of how people define privacy would be interesting, as well as the extent to which people will research DTC-GT companies and their policies during their considerations of genetic privacy.

Aside from a free-response question, the last question asked was whether the respondents would recommend that others use a DTC-GT. The split between “yes” and “maybe” was closer than I anticipated, 47.5% versus 35%. I was expecting there to be a single answer that captured a majority of responses, but instead responses were more evenly split between “yes” and “maybe”. Only 10% of respondents would not recommend using a DTC-GT to others, and 7.5% responded that they did not know if they would make that recommendation. It would be interesting to explore the perspectives of those individuals that responded either “maybe” or “I don’t know” to see if they would recommend the use of DTC-GTs on a case-by-case basis, or if there was some other influencing factor that might result in them changing their response.

The free-response question at the end of the survey was the most interesting to read through. Just over half of the respondents, 55%, decided that they had more thoughts they wanted to share on the topic of DTC-GTs. Some of the overarching themes were that the tests were fun to use, but that they don’t always provide enough information, and that the companies are not well-regulated, nor do they provide much information about how they use the DNA they receive.

On the topic of DTC-GTs being fun to use, one person responded, “It is cool that as the database grows they can update your genetic breakdown!”, which shows both the role that having a large and detailed database plays in creating a detailed analysis, and the joy that an



individual can feel when they gain more information about themselves. Other individuals talked about how easy the tests were to use and how it can be “fun to compare against friends”.

Some individuals complained about the overall accuracy and detailedness of the results, saying, “It’s not as specific as they portray it to be” and “Not enough information on indigenous genealogy (not surprising)”. Especially with this second comment, it connects back to the idea that DTC-GT companies build their databases using submitted samples, and when the databases are lacking in samples from a population, then the results for any individuals in that population are going to be lacking in comparison to those from an individual from a large population that has submitted many samples to a DTC-GT company.

The last of the main themes was that the lack of regulation and information about how DNA samples are used by DTC-GT companies can be concerning. One person brought up the idea that “There should be an age limit, so that minors cannot give away their DNA. I got this test as a gift when I was a minor and did not understand the full extent of what companies can do with the data that DNA provides.” Given that a number of the other survey respondents had also used DTC-GTs before they turned eighteen (32.5%), it does raise the question of whether these individuals were able to provide informed consent, and whether an age limit to ensure informed consent is provided should be considered during the imposition of any future regulations on DTC-GT companies. Another individual raised the idea that “It’s concerning to see this information beginning to be used in criminal cases.” This is a concern that has been raised previously in the literature, and it will be interesting to see whether there will be increased regulations and oversight of law enforcement regarding access to DTC-GT company databases.

There was one response that was especially interesting, as it seemed like this individual really understood the sometimes-damaging impact of conflating the concepts of geographic ancestry and ethnicity:

They lost my sample the first time. Also I mainly did it because I'm interested in my ancestry and family history through what DNA can show me. And the females in my family pushed me to want to know more and to do this and it is interesting. But also I don't like the problematic components of ancestry and similar consumer companies for genetic kits. I think it's especially problematic because of how it allows white people to try and move to innocence (see themselves as innocent in settler colonialism) by seeing DNA that gives them some type of lessened privilege (for example the 1/32 Cherokee trope, or only thinking of the white ethnic relations such as Irish and Italian ethnic groups being stratified historically but now it doesn't matter as much and is used as a trope again). Also that idea for white folks especially to have something "unique" in them by having supposed ancestry to other areas and brings on a lot of trips of tropicality, objectification, fetishization, and dehumanization of Black, Indigenous, and People of Color. Plus what this survey seems to be trying to get at as it is another form of surveillance as well. (Response 7)

This idea of geographic ancestry and ethnicity being separate is something that I am not entirely sure that people entirely understand, and the advertising methods of the DTC-GT companies do not help with that confusion. When individuals immediately adopt the trappings of a culture other than the one they were raised in, based on the strength of a DTC-GT result, it raises questions of whether they truly understand and respect the culture that they are adopting. As this respondent pointed out, some individuals may even use the results of a DTC-GT to excuse either

their own behavior towards a marginalized community or to attempt to push aside the experiences of the people in that marginalized community and invalidate them, due to a belief that they are now part of that community. However, one of the issues with this is people may be basing their belief on a result that indicates a very low probability that they belong to that group, which does not provide them with any of the authority that can be gained from a lived experience in a marginalized community. This is something that really should be discussed in the context of DTC-GTs to make sure that people are truly taking the time to understand what their results mean, and that results of these tests are not being used to negatively impact already marginalized communities.

There were two complete responses that were removed from the analysis. The first was a test to ensure that the survey data was properly recording and could be downloaded for analysis once the survey closed. The second response was removed because the person had chosen to use every opportunity where there was an “other” option with a text box to respond with racist remarks. Unfortunately, because this survey was completely anonymous, there was no other way to respond to this unacceptable behavior. The survey was also open to anyone who had the link, which potentially made it easier for individuals with malicious intent to access, so I was thankful that there was only a single set of hateful responses, because it is possible that there could have been more. This is something I would want to take into consideration with any future survey-based research to minimize access by malicious and racist individuals, while still making it relatively accessible to the focus population.

Overall, when looking at the data collected in this survey, there seem to be multiple avenues that could be pursued in the future given the number of interesting responses and trends. Especially when looking at the number of respondents that said they had previously considered

genetic privacy, I have to think that students seem more likely to understand what they are getting out of their use of DTC-GTs, but less likely to consider or understand exactly what they are contributing, and what that might mean for them.

## **STUDY LIMITATIONS**

This study was comprised of a small sample, which limits statistical analysis. The demographics of the individuals that took the survey were representative of the population that was surveyed; however, the nature of that population means that, had any significant results been found, they could not be applied more broadly without future research to see if the trends held up in larger and more varied populations. Further training in statistics may have made it possible to generate some initial statistical analysis, however the small size of the sample and the structure of some of the questions meant that complex statistical analysis was beyond present skill levels. The size of the sample may have been improved had there been an incentive associated with taking the survey, but the classroom-use only nature of this study meant that there was no funding for incentives. Additionally, this survey was published and shared midway through the spring term, which is a point in the year where students are most likely to be busy with homework and exams and therefore less likely to spend time on a survey that does not have any incentives associated with it.

## **CONCLUSION**

The data generated in this pilot survey has helped to create more questions to guide future research. Initial trends seem to indicate that college students are more likely to receive DTC-GTs

as gifts rather than purchasing the tests themselves, the most common uses are to learn about genealogy and ancestry or for fun, and that many of them have thought about genetic privacy at some point in time. Future research would expand on these results and incorporate the changes mentioned in the discussion section to improve the quality of the results from any surveys run. In addition to a modified survey, which could be distributed to a broader population, adding interviews would provide the opportunity to gain further insight into trends in responses, especially when those trends are different from what had been expected.

One of the most interesting concepts that was revealed by this survey was the cultural concept of gifts and gift-giving. Exploring that concept and how it plays into college student use of DTC-GTs could provide new understanding of how gifts and gifting are viewed by college students, which could be expanded to other types of gifts, not just DTC-GTs. It would also be interesting to focus research on how college students are considering genetic privacy, especially if it encompassed perspectives of both those who have and have not used DTC-GTs. Another thing to examine is how students consider the differences between ethnic and genetic identities, and how often they consider those to be separate identities. There are many different avenues to pursue based on the results of this survey, and I am excited to see what new information will emerge in coming years.

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## Appendix: List of Tables and Figures

Table 1. Participant Demographics

<b>Age</b>	<b>n (%)</b>
18	1 (2.5%)
19	9 (22.5%)
20	8 (20.0%)
21	8 (20.0%)
22	6 (15.0%)
23	1 (2.5%)
24 and over	7 (17.5%)

  

<b>Gender</b>	
Female	25 (59.5%)
Male	8 (19.0%)
Non-Binary	8 (19.0%)
Genderfluid	3 (7.1%)
Transgender	1 (2.4%)
Two Spirit	1 (2.4%)
Prefer not to answer	1 (2.4%)

  

<b>Ethnicity</b>	
White	31 (73.8%)
Asian	7 (16.7%)
Black	3 (7.1%)
Indigenous	3 (7.1%)
Hispanic	3 (7.1%)
Mixed	2 (4.8%)

  

<b>Disability or Chronic Illness</b>	
No	27 (67.5%)
Yes	10 (25.0%)
I don't know	3 (7.5%)

  

<b>Adopted</b>	
No	35 (87.5%)
Yes	5 (12.5%)



Table 2. Respondent Area of Study

<b>Area of Study</b>	<b>n (%)</b>
Biological Sciences	9 (22.5%)
Social, Behavioral, and Economic Sciences	11 (27.5%)
Humanities	8 (20.0%)
Computer and Information Science and Engineering	3 (7.5%)
Other area not listed	2 (5.0%)
Business	2 (5.0%)
Education and Human Resources	2 (5.0%)
Engineering	1 (2.5%)
I don't know	1 (2.5%)
Mathematical and Physical Sciences	1 (2.5%)

Table 3. How Respondents Obtained the Tests

<b>How was the Test obtained?</b>	<b>n (%)</b>
It was a gift	27 (67.5%)
I purchased it myself	13 (32.5%)

Table 4. Age at which the test was used

<b>Age at Which Test Was Used</b>	<b>n (%)</b>
13	2 (5%)
14	1 (2.5%)
15	2 (5%)
16	5 (12.5%)
17	3 (7.5%)
18	5 (12.5%)
19	8 (20%)
20	3 (7.5%)
21	2 (5%)
22	2 (5%)
24 and over	7 (17.5%)

Table 5. Why respondents took the tests

<b>Why did people take the test?</b>	<b>n (%)</b>
To learn about my genealogy and ancestry	37 (88.1%)
For fun	28 (66.7%)
To learn about my medical genetic profile	15 (35.7%)
To learn about my genetic risk factors	10 (23.8%)
To find family members	7 (16.7%)
To support science research	4 (9.5%)
I don't know	1 (2.4%)
I prefer not to answer	1 (2.4%)
Other	1 (2.4%)

Table 6. Reasons Why Disabled or Chronically Ill Individuals Took the Test

<b>Reasons Why Disabled or Chronically Ill Individuals Used the Test</b>	<b>n (%)</b>
For fun	7 (70%)
I don't know	1 (10%)
To find family members	3 (30%)
To learn about my genealogy and ancestry	10 (100%)
To learn about my genetic risk factors	4 (40%)
To learn about my medical genetic profile	5 (50%)
To support science	1 (10%)

Table 7. Reasons why adopted individuals used the tests

<b>Reasons Why Adopted Individuals Used the Tests</b>	<b>n (%)</b>
For fun	1 (20%)
I prefer not to answer	1 (20%)
To find family members	4 (80%)
To learn about my genealogy and ancestry	4 (80%)
To learn about my genetic risk factors	3 (60%)
To learn about my medical genetic profile	3 (60%)
To support science	2 (40%)

## Appendix: Survey Questions

1. How old are you?
2. What is your gender?
  - a. Male
  - b. Female
  - c. Non-binary
  - d. Transgender
  - e. Two Spirit
  - f. Genderfluid
  - g. Genderqueer
  - h. Agender
  - i. I prefer not to answer
  - j. Other not listed
3. What is your ethnicity? (Select all that apply)
  - a. Black
  - b. Indigenous
  - c. Hispanic
  - d. Latine
  - e. White
  - f. Afro-Caribbean
  - g. Afro-Latine
  - h. Asian
  - i. Pacific Islander
  - j. Middle Eastern
  - k. Mediterranean
  - l. Mixed
  - m. I prefer not to answer
  - n. Other not listed
4. Do you identify as having a disability or chronic illness?
  - a. Yes
  - b. No
  - c. I don't know
  - d. I prefer not to answer
5. Were you adopted?
  - a. Yes
  - b. No
  - c. I don't know
  - d. I prefer not to answer

6. What is your area of study?
  - a. Biological Studies
  - b. Computer and Information Science and Engineering
  - c. Engineering
  - d. Geosciences
  - e. Mathematical and Physical Sciences
  - f. Social, Behavioral and Economic Sciences
  - g. Education and Human Resources
  - h. Humanities
  - i. Fine Arts
  - j. Business
  - k. I don't know
  - l. I prefer not to answer
  - m. Other area not listed
  
7. Which direct-to-consumer genetic test kit did you use?
  - a. AncestryDNA
  - b. 23&Me
  - c. I don't remember
  - d. I prefer not to answer
  - e. Other: \_\_\_\_\_
  
8. How old were you when you used the genetic test kit?
  
9. Did you purchase the test kit or did someone else give it to you?
  - a. I purchased it myself
  - b. It was a gift
  - c. It was free and part of a promotion
  - d. I don't know
  - e. I prefer not to answer
  - f. Other: \_\_\_\_\_
  
10. For what purpose did you use the test kit? (Select all that apply)
  - a. To learn about my genealogy and ancestry
  - b. To find family members
  - c. To learn about my medical genetic profile
  - d. To learn about my genetic risk factors
  - e. To support science research
  - f. For fun
  - g. I don't know
  - h. I prefer not to answer
  - i. Other: \_\_\_\_\_

11. If you learned about your genealogy and ancestry, are you satisfied with what you learned?
- Yes
  - No
  - Maybe
  - I don't know
  - I prefer not to answer
12. If you learned about your medical genetic profile, are you satisfied with what you learned?
- Yes
  - No
  - Maybe
  - I don't know
  - I prefer not to answer
13. If you learned about genetic risk factors, are you satisfied with what you learned?
- Yes
  - No
  - Maybe
  - I don't know
  - I prefer not to answer
14. Did you choose to share your DNA profile with the company that made the test kit you used?
- Yes
  - No
  - I don't know
  - I prefer not to answer
  -
15. Did you share your DNA profile with other DNA test companies?
- Yes
  - No
  - I don't know
  - I prefer not to answer
16. Did you read the terms and conditions before using the test kit?
- Yes
  - No
  - I don't know
  - I prefer not to answer

17. Did you understand the terms and conditions before using the test kit?
- a. Yes
  - b. No
  - c. I don't know
  - d. I prefer not to answer
18. Prior to taking this survey, have you ever thought about privacy regarding the sharing of your genetic information?
- a. Yes
  - b. No
  - c. I don't know
  - d. I prefer not to answer
19. Looking back at your experience and what you learned, would you recommend someone else use a direct-to-consumer genetic test kit?
- a. Yes
  - b. No
  - c. Maybe
  - d. I don't know
  - e. I prefer not to answer
20. Is there anything you would like to share about your experience using direct to consumer genetic kits?