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## The Psychosocial Effects of Unexpected Findings on Direct to Consumer Genetic Testing

Emily Wiseman

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**The Psychosocial Effects of Unexpected Findings on Direct to Consumer Genetic Testing**

By

Emily Wiseman

Submitted in Partial Fulfillment of the Requirements

For the Degree of Master of Science in Human Genetics and Genetic Counseling

School of Pharmacy and Health Sciences

Keck Graduate Institute

2020

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**Abstract**

Direct to Consumer (DTC) genetic testing has grown in popularity since its inception in 2010. Consumers can now order DTC tests giving them more information on their ancestry, health and ethnicity than ever before. With more information and more consumers taking the tests, this has allowed for the opportunity of unexpected findings to be generated from the tests. Previous studies have shown that consumers can learn about a health risk they were previously unaware of, and this can impact the health management and surveillance practices of consumers receiving them. Additionally, studies have shown that ethnicity results can impact consumers' previously held perceptions of identity. Ancestry results have the opportunity to reveal misattributed paternity, or differing families of origin than previously known by the consumer, in addition to the discovery of previously unknown close family members. What remains to be determined is the psychosocial effects these unexpected findings have on the consumers who receive them, what they are doing with these results, and how it impacts their daily lives. This exploratory study sought to examine the psychological and social effects of unexpected findings from DTC tests on consumers. This study was conducted via a quantitative survey conducted through Qualtrics, with respondents recruited from the social media platforms of Facebook, Twitter and Reddit. Results found respondents in this study had a high degree of knowledge on genetics and were of above average educational attainment. Respondents main motivation to take a DTC test was personal curiosity, and 42.22% received an unexpected result they felt had implications for their health. Parents were less likely to share their results with their children if they received results they felt were negative in nature. The majority of respondents also elected not to contact a genetic counselor with their results.

*Keywords: DTC, DNA, Direct to Consumer, Genetic Testing, Genetic, psychological, emotions*

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## **Introduction**

As of 2019, over 26 million consumers have taken direct to consumer (DTC) genetic tests, with over 100 million predicted to have taken them by 2021 (Regalado, 2019). With over 40 companies now offering DTC products, and the cost to consumers decreasing every year, these tests are becoming increasingly popular and accessible. While there has been previous research on DTC testing, little has focused specifically on consumers' emotional responses to unexpected DTC results. Furthermore, as the number of consumers taking DTC tests continues to grow, it is paramount to expand upon previous research to increase understanding of the impact of these results.

This exploratory study seeks to gain further information and greater knowledge on the psychosocial effects of unexpected findings on DTC genetic testing. The study aims to do this by measuring consumers' knowledge of genetics, the emotional impact they experience when they encounter an unexpected result, their sharing behaviors, and their perceptions of contacting genetic counselors or other health care providers to answer questions about their results.



## **Literature Review/Background**

### **Definition and History of Direct to Consumer Genetic Testing**

Direct to consumer (DTC) genetic testing began in 2010, with the launch of the first ancestry genotyping test accessible to consumers (Wagner et al., 2012). In the decade since, the market has rapidly expanded, with many more companies offering DTC tests, and the cost per test has also decreased, making tests much more accessible to a wider demographic. DTC genetic testing is defined as genetic testing initiated by the consumer, that is not diagnostic but may include assessments related to health risks, ancestry and/or ethnicity.

Over 40 companies now offer some form of DTC test, and as of 2019, over 26 million consumers had taken tests from the most popular companies (Regalado, 2019). Given that trajectory, data estimates over 100 million people will have taken DTC tests by 2021. These tests are relatively inexpensive, some as low as \$40, making them accessible to a much larger range of individuals--and all the more appealing to the recreational genetics user.

A 2019 Pew Research Center study found that on average one in seven American adults reported using a DTC test, such as Ancestry or 23andMe. Further clarifying their motivations for doing so, researchers found that the majority of those who had taken a DTC test did so to learn more about the origins of their family (87%), slightly more than one-third sought to gain additional personal or family health history (36%), while another 36% also sought to discover or connect with relatives they might not already be aware of. The same study subsequently found that Americans who did not racially identify as white were more likely to be surprised by the findings of their ethnic or racial background (42%). In terms of health findings, 26% of the respondents who described their primary interest in testing seeking health information reported receiving health assessment results they had not anticipated, also found surprises in their health

history they had not anticipated. Additionally, findings indicated that 27% of respondents learned of close family members they had not previously been aware of, through their test results. Lastly, 15% reported their results changed how they viewed or identified their ethnic or racial background (Pew Research, 2019).

### **Motivations for DTC testing**

The accessibility of DTC testing has increased in recent years as has as the number of users who have contributed samples to prominent companies. What is less clear, however, is how consumers are understanding and interpreting their results. A study by Roberts et al. (2017) of consumers who ordered testing through two prominent companies, found that the majority of respondents (74%) were mostly motivated by a desire to know more about their ancestry, followed by seeking information about their traits and disease risk information (72%). Of the consumers interested in learning more about their own disease risk via DTC tests, heart disease, breast cancer and Alzheimer's disease were the conditions of the most interest to consumers (Roberts et al., 2017). A startling 38% of those surveyed said they didn't consider the possibility of unwanted information when they took the test. Meanwhile, a 2016 Swiss study found the main motivation for DTC testing by consumers to be personal utility and entertainment (Chung & Ng, 2016). In another study by Wang et al. (2017) that examined respondents utilizing third party raw data analysis tools to analyze their results; 67% reported feeling highly motivated to examine their results for ancestral information. Another 62% were interested in health implications for the individual, and 40% were interested in both health and ancestry information. A further study on consumers behaviors and motivations surrounding their use of third-party data tools to analyze raw data from DTC results, found that even when individuals were initially motivated to pursue testing out of curiosity surrounding their ancestry, they frequently followed

it up by secondarily pursuing health information as well (Nelson et al. 2019). To further specify their motivations, researchers found that the most common motivation for pursuing DTC testing was general curiosity about genetic makeup (68%) and curiosity surrounding ancestry (66%), followed by family health history (21%) and other family members pursuing testing (11%). Smaller numbers of respondents cited their primary testing motivation as gaining pharmacogenomics information, finding birth families after being adopted, and researching ending dead ends in their genealogical research and professional interest in genetics (Nelson et al. 2019).

### **Ancestry Findings**

The results generated by DTC tests potentially give consumers an experience they didn't bargain for. There are numerous examples of misattributed paternity, defined as the act of discovering that one doesn't have the parentage previously assumed, have been discovered. Popular literature is full of anecdotal accounts of the effects these discoveries have had on the on an individual taking the test--and often an entire family when these results are shared with family members. One such example, detailed in a memoir by journalist Dani Shapiro (2019) recounts the author's experience of learning that she learned she was conceived via sperm donor, after taking a DTC test . The memoir, *Inheritance: A Memoir of Genealogy, Paternity, and Love*, describes the myriad of different emotions Shapiro experienced after receiving test results she had not expected.

Popular culture is filled with personal anecdotes of consumers' experiences encountering unexpected DTC findings that do not fit the categories of health or ethnicity but instead aligned much more closely with Shapiro's story above. One such report, a 2019 *Wall Street Journal* article by Amy Marcus, detailed the experiences of two people who learned through DTC tests

that they had taken simply “just for fun” to learn more about their ancestry with their families, that they were conceived via sperm donor and have a plethora of half siblings they did not know existed. This phenomenon has become so common that there are podcasts and social media support groups dedicated to every kind of test result one can imagine. Not only is this narrative becoming much more common, but there are variations that have the potential to fracture family connections and destroy previously held notions of what one’s parentage looks like. In a 2019 piece for *The Globe and Mail*, Zosia Bielski reports on two such personal stories, in which two individuals learned about unexpected parentage—one the result of previously unknown extramarital affairs and the other adopted in a private, closed arrangement. While these accounts have given an avenue through which extended family has been gained, they have also caused emotional shock and often turmoil—all from the use of a product that was purchased out of novel curiosity.

### **Health Findings**

The surprising results stemming from DTC DNA kits are not limited to parentage or paternity. Other categories of unexpected results are becoming increasingly common. When 23andMe was given permission to add health information on risk factors for ten inherited conditions to their panel in April 2017 (Hayden, 2017), consumers had the opportunity to begin ordering test kits that would not only allow more information on ancestry and their family of origin, but also their presumed risk for certain conditions. Amongst these, in 2015 the Food and Drug Administration (FDA) allowed 23andMe to begin testing for the three most common Ashkenazi Jewish BRCA1 and BRCA2 mutations (23andMe.com). While some studies suggest these three founder mutations account for up to 81% of pathogenic BRCA1/BRCA2 mutations within people of Ashkenazi Jewish descent (Invitae 2019 study; Murphy, 2019), making it useful

for people of origin, it does not identify all of the pathogenic mutations in BRCA1 or BRCA2, and does not inform non-Ashkenazi Jewish consumers about their risk for associated cancers. One such example, recounted by Heather Murphy in *The New York Times* in 2019, details the story of an oncologist who opted for the additional health information panel available on a DTC test and was found to be negative for the tested founder mutations, but still developed breast cancer and only later discovered she had only been tested for the three founder mutations, and had a pathogenic mutation in BRCA that simply wasn't one of them.

Another example, detailed in an article by Schleit et al. (2019), discussed the case example of a woman who received clinical medical diagnostic grade genetic testing and counseling due to a family history of breast cancer. She was found to have a pathogenic BRCA2 mutation. She received post-test genetic counseling, took measures for risk reduction and surveillance, and contacted her siblings to inform them of her results. The following holiday season, she received a DTC kit as a gift. She was surprised, when 23andMe presented her with health panel, that not only did not find she had a BRCA2 mutation, but the result also claimed she had a “lower than average risk” for breast cancer. While a few select Ashkenazi Jewish specific founder mutations are present on the panel, a greater number of mutations applicable to a wider population were not targeted for testing. However, the individual in the article expressed that she felt had she not already had diagnostic grade genetic testing to confirm the presence of the pathogenic BRCA2 mutation, the information she received from the 23andMe test could have caused her to dismiss or overlook her cancer risk (Schleit et al. 2019).

Both of the individuals in the stories above are not alone in their experience. In an April 2019 study conducted by genetic testing and laboratory diagnostic company Invitae on a cohort of 100,000 subjects with a personal or family history of Hereditary Breast and Ovarian related

cancers (HBOC), and 5,000 individuals without such history, 94% of respondents were found to have pathogenic or likely pathogenic mutations within BRCA1/BRCA2 that were not amongst the three most common Ashkenazi Jewish founder mutations (Esplin, 2019). Furthermore, amongst the cohort of 5,000 healthy subjects with no cancer history, 88% of pathogenic and likely pathogenic mutations identified in the previously mentioned genes were missed. These implications suggest DTC cancer mutation screening when limited in the way it currently is presents significant limitations and can offer significant false reassurance for consumers interested in taking charge of their own health information and determining their risks (Esplin, 2019).

While the potential for this false sense of reassurance is currently most applicable to cancer because it is well-known, there are potentially other implications and cases of false assurance, false negatives, and even false positives among other health conditions. Among the set of false positives, consumers examining both health panel results and raw data generated by the DTC tests themselves and exported to third party analysis tools, have the potential to receive false positive results. One such example, discussed by Ellen Matloff in *Forbes*, details the account of a genetic counselor who took DTC tests, and from downloading her raw data--or the specific code of letters and numbers created from genotyping a DNA sample—from her DTC results and analyzed it through a third-party pool. This analysis told her she likely had Lynch syndrome, a hereditary cancer syndrome of the colon, uterus and urinary tract (Matloff, 2019). Through confirmation with medical grade diagnostic testing, she found the raw data had truly been a false positive. However, this illustrates how even an experienced, licensed genetic counselor can be psychosocially challenged when presented with these findings. How much more uncertain are results like this for the average consumer, who does not have extensive training in medical

genetics or knows the differences between medical grade diagnostic testing and how it differs from DTC testing?

Examples of false positives and potential pitfalls within DTC results span beyond anecdotal accounts. A study by Tandy-Connor et al. (2018) examined the false-positive result rate of DTC tests, through a study population of 49 subjects found to have alleged positive pathogenic mutations when their raw data was analyzed. Through clinical confirmation with medical grade diagnostic testing, the study found that 40% of variants previously reported in the raw data results were indeed false positives (Tandy-Connor et al., 2018). While these variants primarily revolved around cancer susceptibility related genes (87.8%), they also included variants in the causative genes for Cystic Fibrosis (8.2%), connective tissue disorders (2%) and Familial Mediterranean Fever (2%). While this is good news for those identified as false positive, the researchers suggest receiving these false positive results can have serious implications for the individuals involved, causing unnecessary stress, changes in medical management, and unnecessary testing of close family members (Tandy-Connors et al., 2018). The researchers also mention that the sample from this study was collected from individuals who had received these results from DTC tests and then shared their results with medical providers who provider determined the results warranted clinical confirmation testing.

False negatives are not unheard of either. A case example was given of one such individual who died suddenly with no previous features of cardiovascular disease, at age 18 (Moscarello et al., 2018). Her family sought answers, and when analyzing raw data from a DTC test she took before her death, believed they found some: the test showed mutations in several genes associated with arrhythmogenic right ventricular cardiomyopathy (ARVC). Her teenage sister was then screened for ARVC, and eventually implanted with an implantable cardioverter

defibrillator (ICD). Later the medical grade diagnostic testing showed she did not have the variant found on her deceased sister's DTC results. With that in mind, the remaining post mortem sample was sent in from the deceased and she was found through medical grade diagnostic testing to not have the variant present on DTC raw data at all. Her sister's ICD was ultimately removed (Moscarello et al. 2018). These are often the outcomes in individuals who do seek out medical providers and have access to further screening and testing. This presents the question of what happens to all those who receive surprising results of this nature but either don't access a medical provider for various reasons--or the provider they meet with is unaware that clinical diagnostics should be ordered to confirm the result.

Hamilton et al. (2016) noted that primary care providers (PCPs) are often the ones presented with DTC test results. While this same study noted that 58% of PCPs believed DTC tests would cause more harm than good for their patients, it doesn't address the question of what actions the providers were taking when presented with the test results. It also had unsettling potential for the affects it could have on the dynamic of patients' lives and their families (Hamilton et al., 2017).

In a revised position statement issued by American College of Medical Genetics and Genomics (ACMG) in 2016, ACMG stated that the consumer should be fully informed about what tests can and cannot tell them about their personal health. The statement further recommends that any information needs to be clearly communicated to the consumer at an appropriate level.

### **Ethnicity Related Findings**

DTC testing also can also affect an individual's previously held notion of ethnicity or racial identity. Roth and Ivemark (2018), interviewed 100 subjects to determine how DTC tests influence consumers in these ways. They found that receiving DTC test results regarding ethnic



ancestry were extremely meaningful for respondents and strongly affected subsequent changes in their sense of self. Results showed that 36% of respondents incorporated geneticized identity, or the ethnic and/or racial identities developed from regions reported on the test results, and 7% of respondents reaffirmed their preexisting identity (Roth & Ivemark, 2018). A unique theme emerged among those who incorporated geneticized identity: they did not abandon their previously held ethnic or racial identity. Respondents often saw these results as scientific confirmation of their previously held notions of identity. Fifty-nine percent discovered new ancestry yet still maintained their previously held identities. Divided into ethnic groups, respondents who identified as exclusively white before DTC testing were more likely (52%) to incorporate results into their identities than those who identified as exclusively black (17%) (Roth & Ivemark, 2018).

### **Social Implications of DTC Unexpected Findings**

What are consumers doing with their DTC test results? How are the results impacting their daily lives? Stewart et al. (2017) found that general psychological response (specified by the researchers as anxiety, distress and worry) were low or absent. However, in some studies it was found that increased perception of control resulted in lower anxiety and distress levels. In another, higher levels of distress correlated with increased genetic risk. An additional two examined studies in their review cited respondents reported a low level of regret regarding their choice to pursue DTC testing. (Stewart et al., 2017). Educational attainment, race and gender were not found to be associated with any of these findings. Stewart et al. (2017) also found that respondents amongst all studies were sharing their results with someone, though the person in which they confided differed: some studies cited disclosure to family or friends were most common, while others found the respondents addressed their results with a health care provider,

most commonly their PCP. In one particular study examined by Darst et al. (2013), those who shared results with a genetic specialist, such as a genetic counselor or geneticist, reported an improved understanding of their results and felt more educated about genetics. Additionally, approximately one-third of those who went to a genetic specialist were more likely to discuss their results subsequently with their physician (Stewart et al., 2017). While the number of findings of adverse psychological responses to the results were low, Stewart et al. (2017) mentioned that these effects when experienced may be significant, and should receive the attention of both the genetic testing companies and the providers meeting with patients. Stewart et al. (2017) recommended that further research needs to be done to identify characteristics of consumers who do and do not experience adverse psychological responses or change behaviors as well as need or decide to pursue additional medical attention, in response to DTC test results.

A study by Middleton et al. (2017) suggested that DTC companies should make a clear offering for post-test counseling services because consumers may not be able to anticipate their psychological needs until they receive a result that causes them anxiety. Additionally, the researchers posit that individuals who received testing may not be able to recognize issues surrounding psychosocial distress as easily, nor the need to seek information on what these results mean for them. The researchers also made the recommendation DTC companies not simply infer for consumers to contact their local genetic counselor. Instead, they suggested companies offer specific resources for where test takers can reach out to a genetic counselor about their results, as there are low geographical concentrations of genetic counselors in many locales, and it could be nearly impossible for a consumer to find one in some places on their own. They end by citing that it is negligence for DTC companies to offer products that can raise anxiety among consumers, but then expect other areas or healthcare to deal with the results

(Middleton et al., 2017). Thus far, at least specifically for consumers ordering their DTC testing through 23andMe, studies conducted in collaboration with the company have yet to provide evidence of adverse effects. A discussion by Eissenberg (2017), however, cites current demographic of users of 23andMe's services skew towards a sufficiently affluent and emotionally, socially and educationally prepared demographic with resources to access healthcare should the need arise to cope with adverse results. An additional study by Broady et al. (2017) found that while some individuals were identified to experience a psychological distress response to their DTC results, they could not identify predictors that indicated which individuals would have these responses.

### **Rationale and Objective of Current Study**

There is still much to be learned about the effects and ramifications of DTC testing on consumers who elect to purchase such products. It is clear that DTC is a new and rapidly developing niche of genetics but also conversely is one that is often the most known and well recognized by consumers. While a consumer may be unfamiliar with genetic counselors or geneticists, they have often heard of DTC genetic testing and many have contributed samples or know someone who has. Based on this widespread popularity, there are plentiful opportunities to receive the unexpected findings listed in the sections above. There is also limited research at this time investigating the psychosocial effects on consumers who take these tests and their behaviors following receipt of results. How do they feel during and after learning their results? How are their daily lives and habits impacted? Who in their family do they share with? Do they aim to seek out a genetic counselor? And what is the science literacy level of demographic of consumers readily submitting these samples? Based on the identified gaps in knowledge in this

area, this study aims to determine the psychosocial effects of unexpected findings on DTC tests on the consumer.

Due to the broad nature of all that has yet to be studied about consumers reactions to DTC tests, this exploratory study seeks to examine the psychosocial effects of receiving unexpected results on these tests. The study aims to do this by examining responses for greater understanding and to identify themes and trends.

## **Materials and Methods**

### **Study Population and Participant Recruitment**

The study population consisted of consumers who had taken a DTC DNA test and received an unexpected result, were over the age of 18, and consented to taking an online survey. Respondents were recruited to take an online survey from social media platforms, including Reddit, Facebook and Twitter. There was no compensation offered for participation in the study. To participate, respondents had to have encountered an unexpected finding in the context of a DTC genetic test result. These unexpected findings were categorized into three groups: Unexpected findings in the family of the origin other than previously known (Ancestry), unexpected results related to ethnic or racial findings that were not anticipated or known previously in the consumers personal identity (Ethnicity), and unexpected findings related to a previously unknown health indicator (Health).

### **Study Instruments**

The study instrument consisted of a 40-item quantitative survey, asking questions about the type of surprising result received, their emotional response to those findings, and who the respondent shared their findings with, if anyone (see Appendix A). Respondents were asked questions such as “Did your results surprise you” and “Did you contact a genetic counselor?” amongst others. The survey instrument was created and launched through the website Qualtrics. Respondents were asked about demographics, what company they took their test from, and then they were subsequently asked a knowledge scale, adapted from a similar scale by Fitzgerald-Butt et al. (2016). The scale was adapted for use in this study by removal of some questions and adapted language. The researcher chose to do this to make the language more accessible to a

general audience. This scale was designed to assess respondent knowledge about genetic concepts.

### **Data Collection and Analysis**

Data collection took place over a period of three months, from December 2019 through March 2020. Data were analyzed via univariate descriptives and bivariate analyses using all available data. Univariate analyses included the calculation of measures of central tendency, (e.g. means), dispersion (e.g. SDs), frequencies and bar charts. Bivariate analyses were deployed to examine the relationships between variables, using the 0.05 level of significance to determine statistical significance, unless otherwise noted. Analyses included independent samples t-tests, one-way ANOVAs, chi-square tests of independence, with supporting values (e.g. degrees of freedom, effect sizes, etc.) reported when necessary. All quantitative analyses were conducted through SPSS software (SPSS Statistics for Windows, Version 26). This study was approved by the Keck Graduate Institute (KGI) Institutional review board as exempt status, protocol #3506.

## **Results**

### **Data Cleaning**

Of the initial 54 respondents, 7 (13.0%) failed to agree to participate in the study and were removed. Another subject (2.1%) was removed due to their skipping the majority of the survey and indicating that they had not taken any DTC genetic tests. All remaining 46 subjects (85.2%) met the minimum qualifications to participate in the study.

The median survey completion time for the remaining 46 subjects was 7.7 minutes, with surveys taking between 2.6 to 20.4 minutes total. The responses of subjects with the lowest response times were scrutinized, but all remaining responses appeared to represent good faith efforts to complete the survey, with minimal missing data.

As a final precaution, a crosstabulation was run in an attempt to identify conflicting responses to the questions “Do you have children?” and “If you shared with your family, what family members did you share with?” It was decided in advance that any respondents indicating that they don’t have children but who later reported sharing their genetic test results with their own children would be removed from the dataset. A single respondent indicated that they didn’t have children but later reported that they told their genetic test results to their child, and was thus removed from the dataset, resulting in a final sample of 45 responses.

### **Participant Characteristics and Demographic Data**

Respondent demographics are included below (see Table 1). Respondents varied in age from 21 to 75 years old. Respondents were both male and female and came from all ethnic backgrounds. Educational completion levels of respondents ranged from high school diplomas through postgraduate education. Respondents reported varied in knowledge of medical genetics and biology. Some had children and some did not.

**Table 1***Demographic Characteristics of Respondents (n = 38 - 45)*

Demographic Characteristics	M (SD)	N (valid %)
Age	45.98 (16.18)	
Genetics Knowledge*	8.52 (1.15)	
Gender		
Male		15 (33.3)
Female		30 (66.7)
Other		0 (0)
Have Children		
Yes		30 (66.7)
No		15 (33.3)
Highest Level of Education Completed		
Some high school		0 (0)
High school diploma		3 (6.7)
Some college		16 (35.6)
Bachelor's degree		12 (26.7)
Some graduate school		1 (2.2)
Master's degree		9 (20.0)
Post graduate degree		4 (8.9)
Test Results Affect Daily Life		
Yes		13 (28.9)
No		32 (71.1)
Type of Unexpected Results		
Ancestry		21 (55.3)
Ethnicity		11 (28.9)
Health		6 (15.8)

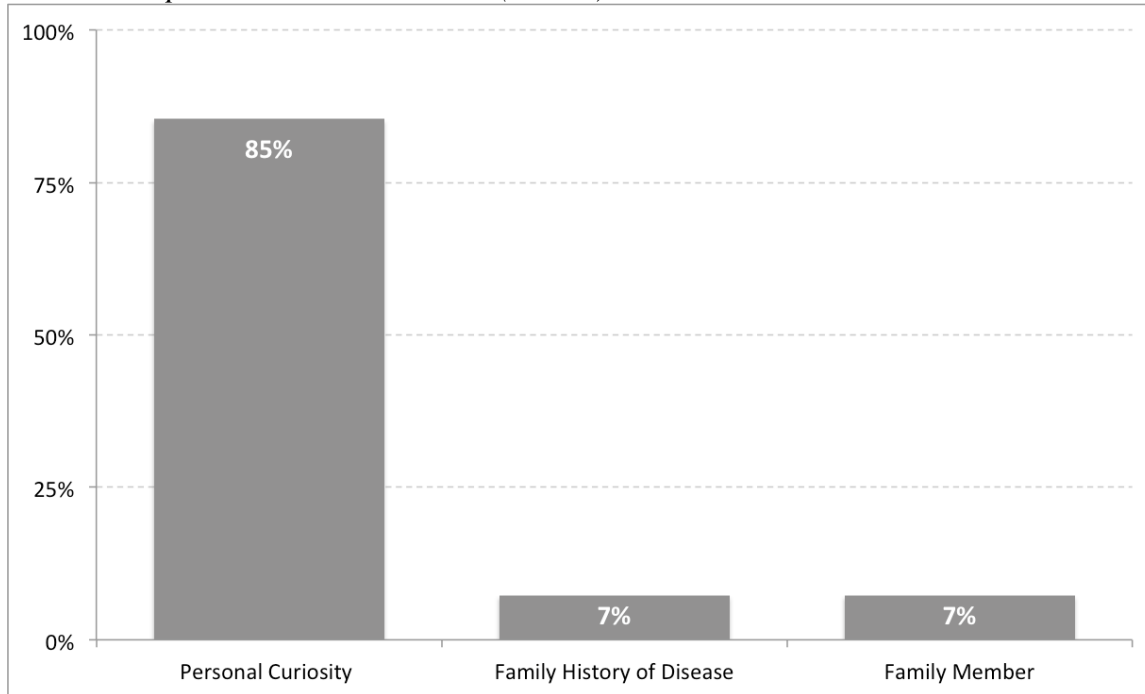
\* Measured on a 9-point scale, where higher score reflects greater knowledge

**Univariate Analyses*****Internal Consistency: Knowledge Index***

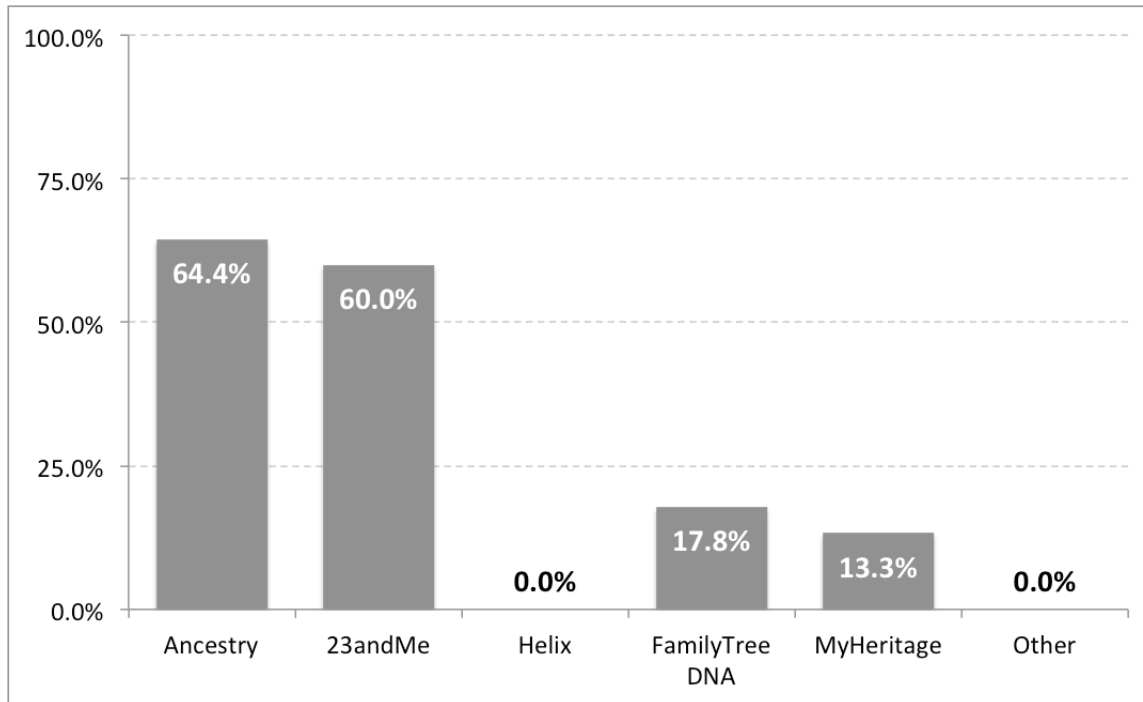
A total of 11 questions were developed to assess respondents' knowledge of genetics. Each question was a dichotomous True/False question, with only a single option serving as a correct answer. Prior to combining these items together as an index, it was decided to run Cronbach's alpha to assess the index's internal consistency. The analysis revealed a low initial internal ( $\alpha = .56$ ) prompting systematic removal of items, one-by-one, to see if the scale's alpha could be shifted into the desired range of  $\alpha = .70-.89$ . Ultimately, the removal of two questions (#6 "A gene is a particle of DNA" and #10 "A person has thousands of genes. Humans have 22 pairs of chromosomes") brought the index's alpha up to .75. Thus, the final index was comprised of 9 questions, yielding possible scores of 0-9.

***Impetus for taking DNA test***



**Figure 1***Reasons Respondents took DNA Tests (n = 41)*

In order to better understand respondents' reasons for taking direct-to-consumer genetic tests a single question was posed to them with three possible response options (see Figure 1). Respondents reported that the most common motivation for taking the test was personal curiosity, followed by an equal percentage electing to take due to a family history of disease, or the encouragement of a family member having also taken a DTC test.

*DNA Test Company Used***Figure 2***DNA Testing Company Used*

In order to better understand which DTC tests respondent used, respondent was asked to indicate which tests they had used from a list of five prominent direct-to-consumer tests with the option to indicate other tests, if necessary (see Figure 2).

**Bivariate Analyses and Patterns of DTC test taking behaviors**

Bivariate analyses were conducted to further explore respondents' responses to develop more themes, trends and data. These will be subdivided into theme areas examined and expanded upon below.

*Knowledge of Genetics and Emotional Responses*

We attempted to determine if there was an association between respondents' knowledge of genetics and their emotional response to their test results, differing between those who

experienced positive (good news, or a health result that revealed no increased disease risk) health findings compared to those who experienced negative (bad news, or a health result that revealed disease risk) health findings.

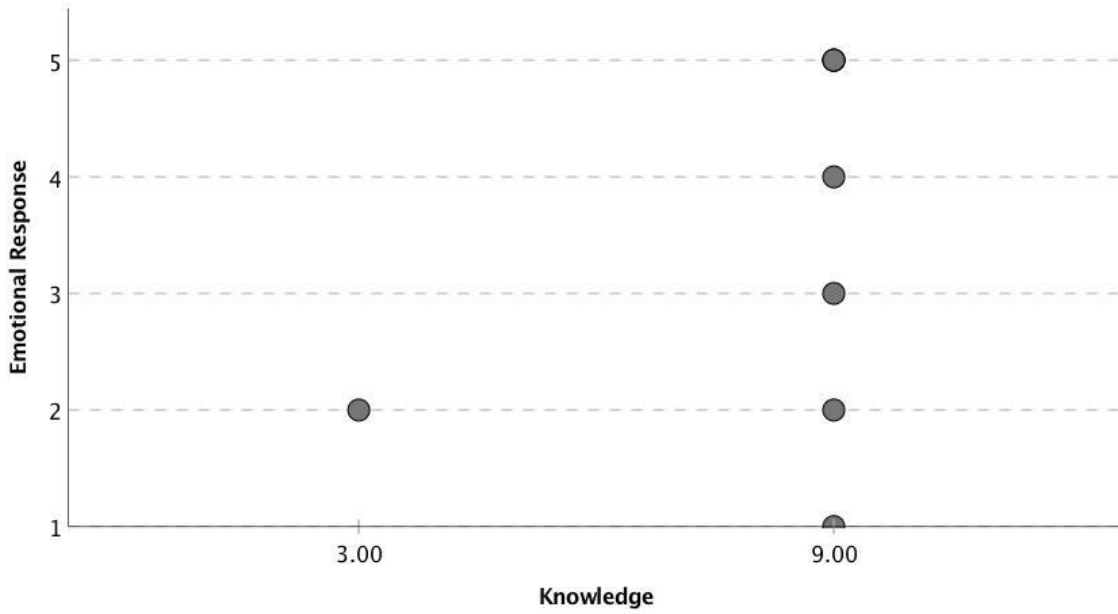
In order to examine how the relationship between genetics knowledge and emotional response to test results is impacted by a third variable, valence of health findings, it was decided to stratify respondents' data by whether they received positive versus negative health findings from their tests. Within each of those strata, the correlation between genetics knowledge and emotional response was then examined.

Amongst respondents with positive health outcomes ( $n=9$ ), there was no statistically significant association between emotional response and genetics knowledge ( $r = .35$ ,  $p = .40$ ). Additionally, amongst respondents with negative health outcomes ( $n = 10$ ), there was no statistically significant association between emotional response and genetics knowledge ( $r = -.20$ ,  $p = .58$ ).

**Figure 3**

*Scatterplot of Emotional Response by Knowledge for Subject Experiencing Positive Health*

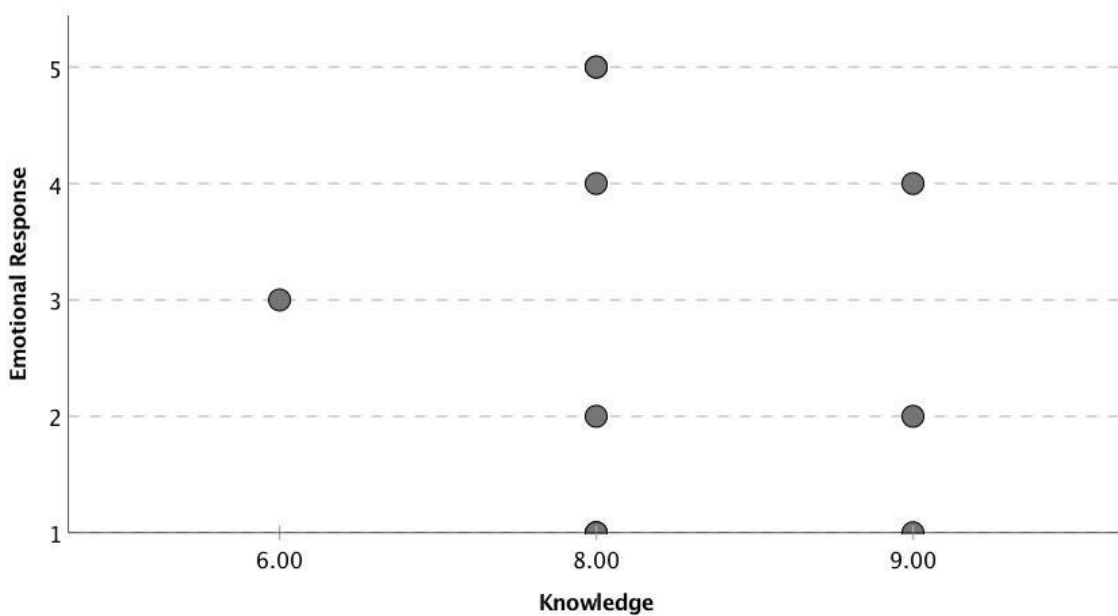
*Results*



**Figure 4**

*Scatterplot of Emotional Response by Knowledge for Subject Experiencing Negative Health*

*Results*



We then sought to determine if respondents' knowledge of genetics differed between those reporting regrets over testing compared to those reporting no regrets. In order to test whether respondents' knowledge of genetics differed between those who expressed regrets over their DTC test compared to those who reported no regrets, an independent samples t-test was conducted. The independent samples t-test revealed, amongst respondents who indicated either the presence or absence of regrets after ordering a direct to consumer genetics test, that there was no statistically significant difference between those without regrets ( $M = 8.49$ ,  $SD = 1.21$ ) compared to those with regrets ( $M = 8.50$ ,  $SD = 0.71$ ;  $t_{(37)} = 0.02$ ,  $p = .99$ ). Nearly all respondents had a high degree of knowledge about genetics.

### ***Type of Result***

All (45) of respondents experienced a result that was surprising. Twelve respondents had a negative or strongly negative emotional response. Fifteen had a positive or strongly response. Ten reported a neutral emotional response to their results. In relation to health result findings, 10 respondents received results they felt had negative implications for their health, while nine received results they felt had positive implications for their health.

We attempted to determine if there was a difference in how unexpected test results impacted respondents emotionally between those reporting surprising results about their ancestry, ethnicity, or health. In order to test whether the emotional impact of surprising test results differed between respondents experiencing results related to their ancestry, ethnicity, or health, a single one-way ANOVA was conducted with the intention of running a Bonferroni post hoc analysis, if warranted. The one-way ANOVA revealed, amongst respondents who experienced surprising test results, that there was no statistically significant difference in the emotional impact experienced between those experiencing surprising results about their ancestry

( $M = 3.90$ ,  $SD = 1.70$ ), ethnicity ( $M = 3.82$ ,  $SD = 1.40$ ), or health ( $M = 2.67$ ,  $SD = 1.21$ ;  $F_{(2, 35)} = 1.53$ ,  $p = .23$ ). We attempted to examine if there was a difference in emotional impact experienced based upon the category of the unexpected result found and were unable to detect a difference between the data set.

### ***Sharing Behaviors***

In terms of who respondents shared their results with, 95.6% (43) shared with family and friends, one shared only with friends, and one elected not to share their results with anyone at all. We examined if respondents' emotional response to their results differ between those who shared their results with their children compared to those who did not. In order to test this, an independent samples t-test was conducted. The independent samples t-test revealed that those who shared their results with their children felt significantly more positive about their test results ( $M = 4.22$ ,  $SD = 1.73$ ) than did those to who did not share their test results with their children ( $M = 2.55$ ,  $SD = 1.29$ ;  $t_{(27)} = 2.76$ ,  $p = .01$ ). People that felt more positively were more likely to share with their children.

### ***Contacting a genetic counselor***

Only three respondents (6.7%) sought out a genetic counselor. Of the respondents who did not reach out to a genetic counselor (93.3%), the most common cited reason was "didn't feel a need to" (35.5%), followed by cost (8.9%), and lack of time (4.4%). Five respondents reported they discussed the results with their PCP but not a genetic counselor, three of which reported subsequent testing or changes to management and care. One reported their PCP would not refer them to a genetic counselor, even after asking with the results in hand.

We examined if there was association between whether respondents sought out a genetic counselor and whether or not they perceived their results as negative for their health. In order to

test this, a chi-square test of independence was conducted. the chi-square test of independence revealed that there was no statistically significant association between whether subjects sought out a genetic counselor and whether or not they perceived their test results as negative for their health ( $\chi^2_{(1)} = 2.01, p = .16, \text{Cramer's } V = .33$ ).

## Discussion

In this section, results discovered from this exploratory study listed in the last section will be expanded upon. Themes of relevancy include demographics of study respondents, motivations for taking a DTC test, genetics knowledge of respondents, emotional response to test results, sharing behaviors and whether or not respondents contacted a genetic counselor.

To better understand the results, we must explore the education of respondents. In this study's sample of DTC testing consumers, we found very high rates of genetics knowledge. Respondents scored a minimum of 3, and a maximum of 9 (perfect score), many had perfect scores. This finding suggests that the knowledge scale, once it had been adapted, may have been too simple and lost its applicability as a validated knowledge scale (Fitzbutt et al., (2016). It is also possible that this self-selected sample was more highly educated about genetics than those in the general population.

Respondents in this study also reported being highly educated in general, as the majority had completed some college or greater, with many even reporting a masters or postgraduate degree completion. This is not representative of the population as a whole, and also mirrors similar findings on education attainment of DTC users in the study Eissenburg (2017). It is also possible those with higher educational attainment are of higher socioeconomic status and therefore have more discretionary income with which to order these tests, which was also supported by the findings in Eissenburg (2017).

Two-thirds (n=30) of respondents were female, which is also not representative of the population as a whole. Two-thirds (n=30) also reported having children. This is interesting finding and a potential explanation may be that people with children had more curiosity of their genetic makeup and what could be passed on to their children in either health or legacy. It could



also be that people with families are more interested in family studies as a whole. There is limited research on this area to support this explanation.

The majority of respondents reported personal curiosity as their main motivation for testing. This parallels the findings on motivation in the study by Cheng and Ng (2016) which cite utility and entertainment as a main motivator for pursuing DTC testing, and reflect many of the motivational findings found by Nelson et al. (2019).

The study may have fell prey to volunteer bias, in which certain respondents systemically were more likely to respond to this survey than others, based on their personal experience relevant to DTC testing. If this is indeed the case, people who received an unexpected result of a certain type, or results that they personally did not perceive as novel or alarming, were less likely to feel they had a story to share and thus felt less inclined to participate in studies like this one. This is also possibly due to the sites at which respondents were recruited: Individuals in this study were located from social media platforms including Facebook, Twitter and Reddit, where they were already present in discussion forums and communications about the topic. It stands to reason that one may be more likely be subject to volunteer bias if contacting a group that received an unexpected result and is eager for answers which have already placed them in the same platform where the study flyer was found.

Reasons for this may be correlated with the above cited main motivation for testing: If respondents took the test solely out of personal curiosity, they may not have been expectant nor prepared for a result other than a novel recap of what they already knew about their own health, heritage or ethnic background. This finding was also cited in the study by Roberts et al. (2017), where respondents did not anticipate the possibility of an unwanted result. In this study, while respondents were surprised by their results, it did not change their lives.

In relevance to health result findings, 10 respondents received results they felt had negative implications for their health, while nine received results they felt had positive implications for their health. One can posit this exemplifies that 19 individuals (42.2%) received additional information about their health that they were not expecting, when they took a DTC test for curiosity. Additionally, 26.7% (12) had a negative or strongly negative emotional responses to their results as whole, regardless of category (ancestry, health, ethnicity) the result fell into. In contrast, 15 (33.3%) had a positive or strongly positive response. Ten (22.2%) reported a neutral emotional response to their results. If one were to assume that no one takes a test out of curiosity expecting the possibility of unwanted news, such as in the study by Roberts et al. (2017), this exemplifies that a large number of respondents, nearly 33%, received news they were not expecting, which emotionally made them unhappy. This could have a huge impact on someone who is just taking a DTC test for fun, and opens the test results expecting to only confirm what they already know. Similar findings were had in the study by Broady et al. (2017) which found that some respondents experienced psychological distress or negative emotions in response to their results.

The independent samples t-test conducted to determine if there was a difference in emotional impact between those who shared their results with their children and those who did not, revealed that there was statistically significant difference: people who felt more positive about their results, were more likely to share them with their children. Reasons for this may include that parents do not want to burden their children with negative information, or share information that has the ability to create confusion or psychological distress. It could also indicate that parents had a sense of shame about their results if they had what the participating parent perceived as negative consequences or implications, and the potential of having passed

something inherited, either in health or family ancestry, to their children. There is no research on this topic at this time to confirm these hypotheses.

Lastly, in the independent samples t-test examining if there was a correlation between whether respondents sought out a genetic counselor and whether or not they perceived their results as negative for their health, no statistical significance was found. However, when reviewing the data set, only 6.66% (3) contacted a genetic counselor regarding their results. Forty-two did not, and many gave reasons for choosing not to do so: Among them, the most commonly cited reasons could be grouped into three major themes, the most prevalent being 15 (35.55%) stating they didn't feel a need to, followed by 4 (8.88%) stating it was cost prohibitive, and 2 (4.44%) reporting a lack of time to contact a genetic counselor. This could provide support for a hypothesis that most consumers who order these tests feel well equipped to interpret the impact of these results themselves, or that they were not familiar with what a genetic counselor is and how to access one if the need arose. There is limited research in this area; however, we do know that density of genetic counselors in most geographic areas is low, as mentioned in the study by Middleton et al. (2017). Another reason this lack of initiated contact with a genetic counselor may be that few DTC companies stress the importance or provide contact resources for genetic counselors for consumers who do receive surprising results on their tests, potentially reducing the chance that the consumer has an idea genetic counseling is available to them (Middleton et al., 2017). Five reported they discussed the results with their PCP but not a genetic counselor, three of whom reported subsequent testing or changes to management and care. One reported their PCP would not refer them to a genetic counselor, even after asking with the results in hand.

The most common reasons respondents in this study cited as to why they elected not to contact a genetic counselor could be beneficial for clinical genetic counselors: if a consumer either is not aware of the practice of genetic counseling, or cannot afford or access services, they may believe they have to interpret any type of DTC surprise alone in a self-guided manner with the assistance of only discussion forums and the internet. In a field as expansive and rapidly changing and developing as genetics, this could prove disastrous. It could also prove beneficial to know these findings on consumer's responses to why they did not seek genetic counseling services, because DTC testing is often the first and only exposure to genetic testing an individual in the general population will have. While a practicing genetic counselor knows the nuances of his or her role, a consumer in the general population may likely not understand the role of a genetic counselor. Knowing this, it gives genetics professionals and the general population a bridge on which to build awareness through productive conversations surrounding genetics and common understanding what genetic counselors truly do.

Some who did not contact a genetic counselor did elect to bring their unexpected findings to a health care provider for consultation, which supports similar findings in the study by Hamilton et al. (2016) discussing where respondents go with their DTC results. Interestingly, our study found 60% (3) of those 5 who consulted their PCP, or 6.66% of the overall sample population, reported subsequent testing or changes to health management and care after giving their provider the results. This begins the discussion of how confident and familiar do PCPs feel with genetics as a whole, and especially what their attitudes surrounding interpreting DTC test results. One reported their PCP would not refer them to a genetic counselor, even after asking to be referred, with the results in hand. This might suggest that PCPs, either correctly or incorrectly, feel

confident interpreting these results and do not feel the need to refer to genetics professionals for further assessment of DTC findings. This is another area of limited study.

### **Future Research**

Findings from this study leaves an opportunity for future research to fulfill in several topic areas which have limited or no previous research. The first outstanding area for future research is approaching a similar study with a validated knowledge scale to better capture consumers' knowledge of genetics. Also allowing for qualitative methods to encourage more themes to emerge through an interview process, instead of limiting respondents to solely what could be recorded in survey items on the internet.

Another area of specific research that could prove beneficial is learning why parents who experienced unexpected results that had a negative impact, elected not to share with their children. The trend was large, but in this study no subsequent questions were asked pertaining to why a respondents declined to inform their children. This behavior pattern could be further explored for the benefit of DTC consumers as a whole, as DTC test taking is often done as a family activity and parents may even be present with their children when they receive results. Questions determining the age of children of parents who declined to share their results could also be expanded upon in future study.

Lastly, the opportunity for motivations in contacting or not contacting a genetic counselor after receiving an unexpected DTC result remains. This study was limited in what it asked of a respondent's motivations for contacting or electing not to contact a GC, and this motivation could be further studied. Learning if consumers who said there was not a need to meant they truly felt skilled enough in medical genetics, risk assessment, and determining a relative's degree of relatedness accurately, to determine these results and the implications for their life; or rather if

they simply felt there was no need because they did not have a desire to discuss their results, or felt it held no implications for their health.

Any of the research suggestions above would be best conducted when recruiting from a more diverse study population than the current study. Also, offering an incentive such as being entered in a gift card drawing, could reduce volunteer bias and allow for a wider genre of consumers to be drawn to the study for more comprehensive and applicable results.

### **Limitations of Study**

The high to perfect score yielded by nearly every respondents on the knowledge scale at the beginning created a limitation in exploring respondents experience with their results.

The limited sample size of the study provides a second limitation. With only 54 total respondents, and then seven of which were eliminated during data cleaning, leaves a relatively small sample that is difficult to derive any statistical significance in the analyses performed. As discussed above in the implications for future research, this provides the opportunity for future study with a much broader sample. The use of incentives, as well as recruiting from different social media platforms, provides an opportunity for greater diversity and size in study respondents. Another opportunity may be for future studies to actively recruit people who took DTC tests over health concerns, to determine if that specific category experienced more emotional effects. Since this study was broad in nature and allowed for responses that fit into health, ancestry or ethnicity related findings, it may have lost some of the specificity that could be yielded from a study solely devoted to only health related findings in conjunction with emotional response.

A third limitation derives from the source of respondents' recruitment. The respondents were collected from social media platforms, including Facebook, Twitter, and Reddit. This indicates

the potential that they were already on these platforms and discussion forums, to seek answers and information regarding their unexpected results. This likely allowed for volunteer bias within those who chose to complete the survey, and is not representative of DTC testing consumers as a whole. It is also important to note that posting the survey flyer on Reddit was challenging, as it was frequently taken down by “bots”, or automated processes within the discussion forums present to detect spam or junk posts. The study was taken down nearly every time posted, within a 24-hour period. It had to be reposted frequently to be able to reach an audience.

A final limitation derives from the timeline of research conduction. Respondents were recruited and the study posting itself from start to finish only were present on the internet for three months, from December 2019 to March 2020. Had the study had one to two years to recruit, it is likely it could have been a vastly larger sample size which could have yielded additional information and results.

### **Conclusion**

This exploratory study aimed to examine the psychosocial effects of unexpected results from direct to consumer genetic testing, upon the consumers who received them. Based on a quantitative analysis of survey results from consumers who had taken DTC tests, it can be concluded that many trends and themes emerge when surveying respondents about their emotional response and post-test experience.

The study was conducted through recruitment on social media platforms of consumers who had taken DTC tests, and completed a survey asking them questions about their experience. The results indicate that the majority of consumers who order DTC tests are motivated by personal curiosity. The results additionally indicate that respondents are less likely to share results with negative implications with their children. The study reflects that a very low number of consumers reach out to a genetic counselor to discuss their results, but that a small minority do present them to their primary care provider. The study attempted to determine if there were differences in a respondent's knowledge of genetics and the emotional response they experienced with their unexpected result, as well if there was a difference in the emotional impact experienced based on the category (ancestry, health or ethnicity) of unexpected finding present. However, this study was unable to detect differences in the data set in each instance. In the study, the majority of respondents received exceptionally high scores on the knowledge scale used to determine their knowledge of genetics, with most receiving a near perfect or perfect score. While the small sample size and high knowledge score limits the generalizability of the results, it provides new insight into the experience surrounding DTC testing.



Further research is needed with a larger, more diverse sample size to determine if these results are generalizable. Additional research is also needed to determine why parents are less likely to share their results with their children if they have negative implications.

The findings in this study, while small, confirm previous research surrounding consumer motivations for DTC testing, as well as further explore the limited area of study regarding who consumers share their results with. This study also exemplifies how few of consumers, even when faced with a result they were not anticipating, contacted a genetic counselor to discuss their results. The findings of this study lend themselves to greater conclusions and opportunities for subsequent research in more specific areas of each theme discussed above, that will benefit not just consumers but clinical counselors in their understanding of the consumer experience surrounding DTC testing.

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**Appendix A: Adult survey**

**Examining the psychosocial effects of unexpected findings on the direct to consumer tests**

Q40 [Kgi consent form clean copy 12519 1](#) Please review the informed consent form first

Q41 I have read and consent to the terms of the informed consent above:

Yes (1)

No (2)

Q1 What is your age?

---

Q2 What gender do you identify as?

---

Q3 What is your ethnic background?

- Caucasian (1)
- African American or Black (2)
- Asian or Pacific Islander (3)
- Native American or Alaskan Native (4)
- Other (5) \_\_\_\_\_

Q4 Are you Hispanic or Latino?

- Yes (1)
- No (2)

Q5 Do you have children?

- Yes (1)
- No (2)

Q6 What is your highest completed level of education?

- Some high school (1)
- High school diploma (2)
- Some college (3)
- Bachelor's degree (4)
- Some graduate school (5)
- Master's degree (6)
- Post graduate degree (7)

Q7 What DNA test company did you use?

- Ancestry (1)

- 23andMe (2)
  - Helix (3)
  - FamilyTree DNA (4)
  - MyHeritage (5)
  - Other, please specify: (6)
- 

Q8 Do you have a formal educational background in human genetics and biology?

- Yes (1)
- No (2)

Q9 Please indicate whether the following statements are true or false:

	True (1)	False (2)
Some diseases are caused by interactions of living environment, genes and behaviors (1)	<input type="radio"/>	<input type="radio"/>
A gene is the same as a disease (2)	<input type="radio"/>	<input type="radio"/>
Healthy parents can have a child with an inherited disease (3)	<input type="radio"/>	<input type="radio"/>
A person with a mutated gene may be completely healthy (4)	<input type="radio"/>	<input type="radio"/>
Genes are instructions for making proteins, which help the body grow and function normally (5)	<input type="radio"/>	<input type="radio"/>
A gene is a particle of DNA (6)	<input type="radio"/>	<input type="radio"/>
Genes are inside of cells (7)	<input type="radio"/>	<input type="radio"/>
A chromosome contains many genes (8)	<input type="radio"/>	<input type="radio"/>
Genes determine traits such as height, eye color, and facial appearance (9)	<input type="radio"/>	<input type="radio"/>
A person has thousands of genes. Humans have 22 pairs of chromosomes (10)	<input type="radio"/>	<input type="radio"/>
A genetic test can tell you if you have a higher chance to develop a specific disease (11)	<input type="radio"/>	<input type="radio"/>

Q10 What prompted you to take the DNA test?

- Self-curiosity (1)
- Known family history of genetic disease (2)
- Family member (3)
- None of the above (4)

Q11 Have you had any friends or family who have taken a DNA test like the one you took?

- Yes (1)
- No (2)

Q12 Did you learn anything from the DNA test you weren't expecting?

- Yes (1)
- No (2)

Q13 If yes above, what category would this unexpected information fall into?

- Ancestry (1)
- Ethnicity (2)
- Health (3)

Q14 Emotionally, how did viewing those results make you feel?

- Strongly Negative (1)
- Negative (2)
- Neutral (3)
- Positive (4)
- Strongly positive (5)

Other: (6) \_\_\_\_\_

Q15 If other, please specify:

Q16 Did the results affect your daily life?



No (1)

Yes (2)

Q16 If yes, please specify:

---

Q17 Did these results affect your perception of your overall health?

Yes (1)

No (2)

Q18 If the results impacted your perception of your overall health, were they positive or negative?

Positive (1)

negative (2)

Q19 Have you shared or discussed those findings with your family?

Yes (1)

No (2)

Q20 If you shared with your family, what family members did you share with?

- Significant other (1)
- Parents (2)
- Child (3)
- Sibling (4)
- Aunt/Uncle/Cousin (5)
- Close friend (6)
- Coworker (7)
- Grandparent (8)
- Other: (9) \_\_\_\_\_

Q21 If other, please specify:

\_\_\_\_\_

Q22 If you did not share the findings with your family, what was your reasoning for doing so?

- Privacy (1)
- Shame (2)
- Unsure how they would react (3)
- Haven't had an opportunity to do so yet but plan to (4)
- Other: (5) \_\_\_\_\_

Q23 Did you seek out a genetic counselor to discuss the results?

Yes (1)

No (2)

Q24 If no, why?

---

Q25 If yes, why?

---

Q26 If you didn't discuss your results with a genetic counselor, who did you discuss them with?

---

---

Q27 If you discussed them with the individual above, what was their response?

---

Q28 Do you have any regrets about the direct to consumer DNA test?

Yes, please specify: (1) \_\_\_\_\_

No (2)

Q30 Did you upload your genetic data to any websites? If yes, which ones?

---

Q31 If you uploaded your data to a third-party raw data analysis site, how did you find out about the site?

---

Q32 What prompted you to download your raw data and upload it to the site?

- A desire to find out more about your health data (1)
  - A family member who has a genetic condition (2)
  - Other, please specify: (3) \_\_\_\_\_
  - Non-applicable (4)
- 

Q33 What did you expect to find/learn from uploading your data?

\_\_\_\_\_

Q34 Was the information you learned from your DNA test unexpected?

- Yes (1)
- No (2)

Q35 If yes, how so was it unexpected?

\_\_\_\_\_

Q36 Did the results from the DNA test change your perception of your ancestry or ethnic background?

- Yes (1)
- No (2)
- Other, please specify: (3) \_\_\_\_\_

Q37 If other, please explain

\_\_\_\_\_

Q38 Did the results from the DNA test change your perception of your family and who you are related to?

Yes, please explain: (1) \_\_\_\_\_

No (2)

c. Other, please specify: (3)  
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**Appendix B: Consent Form****AGREEMENT TO PARTICIPATE IN *DIRECT TO CONSUMER SURVEY* (IRB # 3506)**

You are invited to participate a research project. Volunteering will not benefit you directly, but/and you will be helping the researchers better understand the feelings that result from surprises on direct to consumer tests. If you volunteer, you will you will take a survey, which will take about 30 minutes of your time. Volunteering for this study involves minimal risk. Your involvement is entirely up to you. You may withdraw at any time for any reason. Please continue reading for more information about the study.

**STUDY LEADERSHIP:** This research project is led by Emily Wiseman, a Masters of Human Genetics and Genetic Counseling student at Keck Graduate Institute and Emily Quinn, MS, who is supervising her.

**PURPOSE:** The goal of this study is to better understand the experiences consumers may have with emotional distress resulting from unexpected results found through direct to consumer DNA testing. You will be asked to answer questions such as “what was your previous knowledge of genetics?” and “did you share your test results with your family?”

**ELIGIBILITY:** You must be over the age of 18.

**PARTICIPATION:** During the study, you will be asked to During the study, you will be asked to fill out a survey. This will take about 30 minutes.

**RISKS OF PARTICIPATION:** The risks that you run by taking part in this study are very minimal. These risks include finding some of the questions to be upsetting, particularly those related to your experience with your unexpected DNA test finding.

**BENEFITS OF PARTICIPATION:** We do not expect the study to benefit you personally. This study will benefit the researchers by better understanding the emotional impact of unexpected findings found on direct to consumer DNA tests.

**COMPENSATION:** You will not be directly compensated for participating in this study.

**VOLUNTARY PARTICIPATION:** Your participation in this study is completely voluntary. You may stop or withdraw from the study or refuse to answer any particular question for any reason at any time without it being held against you. Your decision whether or not to participate will have no effect on your current or future connection with anyone at Keck Graduate Institute or any of the other Claremont Colleges.

**CONFIDENTIALITY:** Your individual privacy will be protected in all papers, books, talks, posts, or stories resulting from this study. We may use the data we collect for future research or share it with other researchers, but we will not reveal your identity with it. In order to protect the confidentiality of your responses, We will remove names and identifying information from the surveys collected.

**FURTHER INFORMATION:** If you have any questions or would like additional information about this study, please contact Emily Wiseman] at (928) 607-0386 or [ewiseman18@students.kgi.edu](mailto:ewiseman18@students.kgi.edu). You may also contact Emily Quinn at (909) 607-6474 or [Emily\\_Quinn@kgi.edu](mailto:Emily_Quinn@kgi.edu). The CGU Institutional Review Board certified this project as exempt. If you have any ethical concerns about this project or about your rights as a human subject in research, you may contact the CGU IRB at (909) 607-9406 or at [irb@cgu.edu](mailto:irb@cgu.edu). A copy of this form will be given to you if you wish to keep it.

**CONSENT:** Your check box below means that you understand the information on this form, that someone has answered any and all questions you may have about this study, and you voluntarily agree to participate in it.

Check box of participant checking yes or no for participation:

Yes\_\_ No\_\_

Date \_\_\_\_\_

Printed Name of Participant \_\_\_\_\_

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