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Americans' Familiarity, Interest, and Actions with Direct-to-Consumer Genetic Testing

by

Riley L. Carroll

A thesis submitted in partial fulfillment
of the requirements for the degree of
Master of Science in Public Health
with a concentration in Genetic Counseling
College of Public Health
University of South Florida

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Abstract

Background: In 2013, 36% of the U.S. public was aware of Direct-to-Consumer (DTC) genetic tests, but updated studies are needed to identify whether this has changed over time. *Objective:* The aims are to determine current awareness and utilization of DTC tests and to identify demographic factors that influence testing uptake. *Methods:* An online panel survey of 543 U.S. adults was conducted using age- and sex-based quotas. Descriptive statistics and binary regression identified factors associated with undergoing DTC testing and linear regression was conducted to identify factors associated with likelihood of using DTC testing for athletic ability to change behavior related to athletics. *Results:* 84% of participants were aware of DTC tests, but only 12% used them. For those who did, 63.2% conducted their own Internet investigation of the results while 13.2% spoke with a medical professional and 4.4% met with a genetic counselor. Identifying as politically liberal was significantly associated with testing after controlling for awareness of genetic counselors, sex, income, race, years of education, age, and science knowledge scores yet all variables explained only a small amount of variation ($R^2 = 0.047$). Positive attitudes towards DTC testing for athletic ability along with male gender, younger age, and lower science knowledge scores were statistically associated with how likely they would be to use such results to change their behavior ($R^2 = 0.45$). *Conclusions:* Awareness of DTC genetic tests have continued to increase but completion rates remain low. Most who had DTC genetic

testing do not speak to experts though many seek additional information online.

Sociodemographic factors do not explain DTC testing uptake but positive attitudes about testing substantially increase the likelihood that results would change behavior.

Introduction

In the past, genetic tests were strictly offered by healthcare professionals, however people now have access to them through direct-to-consumer (DTC) genetic testing companies (Goldsmith et al., 2012). The public has shown interest in DTC genetic testing to determine potential health risks, seek information about their racial/ethnic ancestries, and general curiosity. Consumers also state concerns over privacy and the reliability of the tests (Goldsmith et al., 2012; Su, 2013). Specifically, most consumers of DTC genetic testing reported that while the public should have access to these tests, the companies should be monitored to ensure that their results are scientifically accurate (Bollinger, Green, & Kaufman, 2013).

The latest investigation on the national awareness of DTC genetic testing was published in 2015 using data gathered from the 2013 U.S. Health Information National Trends Survey which determined that approximately 36% of the public were aware of DTC genetic tests (Agurs-Collins et al., 2015). This is different from another study which used participants recruited by the Northwest Cancer Genetics Network (NCGN) who had either a personal and/or family history of cancer and found that 49% were aware of DTC genetic tests and that, of those who were aware, 19% were interested and less than 1% had completed DTC genetic tests (Hall et al., 2012). Differences between the 2013 U.S. Health Information National Trends Survey and the NCGN study could potentially be explained by differences in populations surveyed given that the NCGN included participants specifically with personal and/or family histories of cancer. Regardless, it has been several years since the awareness of DTC genetic tests has been studied.

Public awareness of DTC genetic tests may have increased, but there is limited prior research regarding consumers' motivations for DTC genetic testing. One follow-up on the Impact of Personal Genomics (PGen) study found that most consumers were interested in ancestry information yet many also perceived personal utility of the results including empowerment over their health (Roberts et al., 2017). Other perceived benefits of DTC genetic testing include access, low cost, and confidentiality from medical professionals and health records among others (Ayala-Lopez & Nichols, 2020). Nevertheless, there are several concerns about DTC genetic tests which include emotional burdens, accuracy, reliability, and clinical utility, or medical relevance and usefulness (Su, 2013). Specifically, self-misdiagnosis and confusion over the results were major concerns (Ayala-Lopez & Nichols, 2020). Consumers of DTC genetic tests should be aware of the scope and limitations of these types of tests since that could affect their interest in testing. The Northwest Cancer Genetics Network study found that participants with a strong family history of cancer reported more interest in DTC tests though it is uncertain whether consumers understand these tests are incomplete assessments of genetic risk and may not have clinical utility (Hall et al., 2012).

In addition to motivations, it would be important to determine if there are demographic factors that influence DTC testing utilization. The original PGen study examined 23andMe and Pathway customers and found that the majority were college-educated white females of high economic status (Koeller et al., 2018). However, significance of these associations was not reported. A similar study on adult Kaiser Permanente members determined that rates of testing were similar across races (Carroll et al., 2019). It is unclear if there are demographic factors that predict use of DTC genetic testing which would be vital to find out if this also influences how they use the results.

Prior research has focused on who consumers speak to about their DTC test results. In the PGen study, 4% met or planned to meet with a genetic counselor, and 46% shared the results with another medical professional (Koeller et al., 2018). The Kaiser Permanente members found that 17% of participants received DTC genetic testing and, of those that received an abnormal result, 73% spoke with a medical professional in which 43% specifically met with genetic counselors (Carroll et al., 2019). While the Kaiser Permanente study found similar rates of testing across races, the PGen study demonstrated non-Hispanic Whites were more likely to speak with a medical professional than Hispanics and non-Hispanic Blacks (Carroll et al., 2019; Koeller et al., 2018).

Other actions taken with DTC test results are not well known. The majority of the PGen participants reported that test results would affect health management (Ayala-Lopez & Nichols, 2020). However, additional analysis found that DTC results led to moderate positive diet and exercise changes (Nielsen, 2017). This is consistent with another study which showed that few of the 20 participants used DTC results to make positive health changes, but many stated that the results did not impact them significantly (Wasson et al., 2013). Consumers also find utility in genetic testing for sports and athletic ability as evidenced by a study showing approximately 80% of athletes and support staff thought genetic testing was valuable for predicting sport performance and helpful in reducing injuries (Varley, 2018). Another recent development involves third-party companies that interpret raw data from DTC genetic test results. Up to 62% of DTC genetic testing consumers utilize these services yet it offers limited medical utility since one study found 40% of the 49 pathogenic or likely pathogenic variants sent to labs for clinical confirmation were false positives (Moscarello et al., 2019; Tandy-Connor et al., 2018, Wang et al., 2018). This is because DTC genetic tests utilize single nucleotide polymorphism (SNP) based

technology that look for common variants found in the population rather than DNA sequencing methods used by diagnostic laboratories. One study investigated over 1,000 pathogenic and likely pathogenic *BRCA* variants in the UK Biobank and found that the sensitivity and positive predictive value for SNP chip-based testing was 34.6% and 4.2% respectively for rare *BRCA* pathogenic variants. The study not only supports clinical confirmation but urges that individuals with a strong personal and/or family history of breast and/or ovarian cancer and negative DTC genetic testing should be aware of the limitations of such testing (Weedon et al., 2021). These studies show that individuals believe DTC genetic test results have personal utility and consumers should be educated about how little insight these tests can give because they fail to assess a whole host of genetic and environmental factors.

The U.S. public's awareness and perceptions regarding genetic counseling was assessed in a survey of questions on a variety of topics including questions about DTC genetic testing (Pasca et al., 2020). Participants from prior studies have been focused on health or have prior experience in genetics and those studies did not evaluate where they obtained more information beyond seeing a genetic counselor or other medical professionals (Carroll et al., 2019; Hall et al., 2012; Koeller et al., 2018). The purpose of this study is to analyze the participants' awareness, interest, and uptake of DTC genetic testing, identify actions taken with results beyond seeing a medical professional or genetic counselor, elicit demographic variables that are significantly associated with having undergone testing, and identify the role of attitudes toward development of DTC testing for athletic ability on behavioral intention.

Methods

Participant recruitment and data collection

The study participants were recruited through an online panel survey conducted from September 2019 to October 2019 through Qualtrics using quotas for age and sex that are representative of the general U.S. population. The study was approved through the University of Tampa's Institutional Review Board (IRB). Participants were provided an informed consent document stating that participation was voluntary, personal information was not being collected, each participant was assigned a random ID, the survey would approximately take 15 minutes, and continuing to the survey questions indicated that participants read and gave their informed consent. The survey used adaptive questioning so that participants were only asked certain questions based off their responses to others. No personal identifiable information was collected.

Measures

Sociodemographic and Science Knowledge The survey included questions on age, sex, income, race, marital status, religious service attendance (“Never,” “A few times a year,” or “Once a month or more”), education (measured on level of formal education), and political views (rating themselves on a scale from “Extremely liberal” (1) to “Extremely conservative” (7)). Science knowledge was also measured using five different statements that required participants to respond with either “Yes,” “No,” or “Don’t Know” with correct answers scoring a 1 and incorrect and “Don’t Know” scoring a 0 for a total score ranging from 1-5. Awareness towards genetic counseling was assessed by answering “Yes” or “No” to if they had heard of the

profession and, if they selected “Yes,” they had to write in their understanding of the roles of genetic counselors (Pasca et al., 2020).

Direct-to-Consumer Genetic Testing Awareness, Intent, and Actions After a short description was provided concerning DTC genetic testing companies, the participants were asked, “How familiar are you with these companies?” They were then able to select either “I have had my DNA analyzed by one (or more) of these companies,” “I have seriously considered having my DNA analyzed by one (or more) of these companies,” “I am familiar with the services these companies provide and have considered having my DNA analyzed,” “I am familiar with the services these companies provide but have not considered having my DNA analyzed,” “I’m not familiar with the services these companies provide,” or “Other.” If participants selected the first response, they were then asked, “As a result of your DNA testing, which of the following have you done (select all that apply).” The available responses were “consulted a physician or other medical professional concerning my results,” “looked up information on the results of my test online,” “downloaded my raw DNA data and submitted it for additional analysis,” “met with a genetic counselor,” “contacted the company that provided the testing for more information,” and/or “had additional genetic testing done.”

Attitudes and Behavioral Intention to Use Genetic Testing for Information Related to Athletic Ability Two questions measured the participants’ attitudes towards and likelihood to use genetic tests for information on athletic ability. Specifically, the first question asked, “Some research suggests that there are genes that are more common among athletes. If a test were developed that could be used to determine whether an individual would be more or less likely to excel at certain sports, how would you view such a test?” Responses included, “A completely positive development,” “A positive development with some drawbacks,” “A development with

an equal balance of benefits and drawbacks,” “A troubling development with few benefits,” and “A completely troubling development.” The second question asked, “If a test existed that indicated people were more or less likely to excel at certain sports, how likely would it be that such information would change your own behavior?” Responses were on a scale from “Extremely unlikely” (1) to “Extremely likely” (7).

Data Analysis

A total of 582 participants completed the survey. After removing 39 respondents due to inaccurate answers on attention check questions, a total of 543 participants remained for the analysis. Data were analyzed using SPSS 24.0 and results were considered statistically significant at an alpha level of 0.05. Frequencies were calculated for those who underwent DTC genetic testing and those who did not, and binary logistic regression was done to identify which factors (age, sex, race, political views, years of education, awareness of genetic counseling, income, and science knowledge scale) were significantly associated with having undergone DTC genetic testing versus others. For political views, two dummy variables were created that used conservatives as the reference group to which both liberals and moderates were compared. Ordinary least squares (OLS) regression was done to determine if attitudes towards DTC athletic ability results and other demographic variables were significantly related to behavioral intention to use DTC athletic ability results.

Results

Among the 543 participants who fully completed the survey, 68 (12.5%) had undergone DTC genetic testing, 187 (34.4%) were familiar with DTC genetic tests and had previously considered being tested, 197 (36.3%) were familiar and had not previously considered being tested, and 91 (16.7%) were unfamiliar with DTC genetic testing. Thus, a total of 452 (83.3%) were at least aware of DTC genetic tests, but a much smaller percentage of these had undergone testing. Demographics for those who had testing and those who did not are shown in Table 1. Both groups mostly consisted of white participants, 86.8% and 78.7% respectively. The mean age of those tested was 48.8 while those not tested had a mean age of 46.2. Both groups demonstrated an even split between males and females with a slightly lower proportion of males in the group that had not accessed testing. Larger differences were seen across groups in terms of political views with the testing group being comprised of 31 (45.6%) liberal, 20 (29.4%) moderate, and 17 (25.0%) conservative individuals while the untested group consisted of 137 (28.8%) liberal, 184 (38.7%) moderate, and 154 (32.4%) conservative individuals. Income was relatively evenly distributed in the tested group but varied more in the untested group with 225 (47.4%) earning less than \$50,000, 153 (32.2%) earning between \$50,000 to \$99,999, and 97 (20.4%) earning more than \$100,000. Awareness of genetic counseling was higher in the tested group compared to the untested group (22.1% vs 12.2%). In addition, average years of education was 15.21 and the mean on the Science Knowledge Scale was 3.29 among those tested while the

average years of education was 14.25 and the mean on the Science Knowledge Scale was 2.72 in the untested group.

Actions taken with the DTC genetic test results by those who were tested are summarized in Table 2. Participants were provided with a list of select responses with what they did with their DTC genetic test results with the ability to select more than one. Most participants, 63.2%, looked up their information online, 13.24% consulted a physician or medical professional while 4.41% met with a genetic counselor.

Results of the binary regression analysis conducted to determine if there were any demographic differences between those who were and were not tested are shown in Table 3. Liberals were nearly two times as likely as conservatives to undergo DTC genetic testing (OR: 1.992 [1.021-3.887], $p = 0.043$) when controlling for other demographic variables. No other statistically significant relationships were found. The adjusted R^2 value for the binary regression analysis was 0.047 indicating that variables in the model explained less than 5% of variability in undergoing DTC genetic testing.

Results of the OLS regression analysis found several factors that were significantly associated with behavioral intention to use genetic test results related to sport performance (Table 4). Individuals were more likely to intend to use results if they reported positive attitudes towards DTC testing for sport performance ($b = 1.007$, $p < 0.001$), if they were male ($b = -0.275$, $p = 0.047$), if they were younger ($b = -0.023$, $p < 0.001$), and those with lower scores on the science scale ($b = -0.146$, $p = 0.002$). No other statistically significant relationships were found. The adjusted R^2 value for the OLS regression analysis was 0.44.

Discussion

Results of this study suggest that national awareness for DTC genetic testing has increased over time with 84% being aware in 2019 compared to 36-49% awareness in studies conducted over 8 years ago (Agurs-Collins et al., 2015; Hall et al., 2012). Our study found that 12.5% had undergone DTC genetic tests and 34.4% of participants were at least interested in them which suggests an increase from the NCGN study where less than 1% underwent testing while 9% were interested (Hall et al., 2012). Overall, these results suggest that awareness and interest in DTC genetic tests has increased substantially while testing rates remain low.

Those who were tested showed overall higher income, more awareness of genetic counseling, more years of education, higher science knowledge scores, and were more likely to report being liberal, but only the latter achieved statistical significance in the regression model. The PGen study noted that many of the participants who had testing earned a household income greater than \$100,000 (Koeller et al., 2017). A possible explanation for this is that the cost of DTC genetic testing has declined in recent years, which has made it more accessible to the general population. It may also be that the sample of those who were tested was small, thereby limiting power to detect differences. The Kaiser Permanente study demonstrated that non-Hispanic Asian/Pacific Islanders were significantly less likely than non-Hispanic whites to utilize DTC genetic testing (Carroll et al., 2017). Despite only assessing White or Non-White on the survey, the results of this study did not reveal that race was a significant predictor for DTC genetic testing which is consistent with the previous investigation. The only variable that

remained significant in the regression was political views with liberals being nearly twice as likely as conservatives to have undergone DTC testing. This aligns with prior research on political views which showed that intolerance to new experiences and to uncertainty were associated with conservative views (Jost et al., 2003). This offers a possible explanation about why conservatives are significantly less likely to undergo DTC genetic testing than liberals since genetic testing is a new experience and the results can lead to uncertainty. Nevertheless, the adjusted R^2 score for the regression analysis was weak (0.047) which means that despite being statistically significant, political views and other demographic variables explain very little of the variation in whether someone will undergo DTC genetic testing, suggesting there are unmeasured factors that are contributing to DTC testing uptake among our participants.

In contrast, the OLS regression analysis found that males, younger participants, lower science knowledge scores, and positive attitudes toward genetic testing for athletic ability were all significantly associated with the reported likelihood they would use the results of DTC genetic testing to change their behavior regarding athletics. This suggests that attitudes towards DTC genetic testing is a major contributor to how people value the results and if it would influence their lives. Prior research has demonstrated that DTC genetic test results have an impact on behavior. Around 60% of PGen participants who underwent DTC genetic testing reported they would use the results for health management purposes (Roberts et al., 2017). Since DTC genetic testing does not provide much insight into genetic and environmental factors, it is somewhat concerning that males, younger individuals, lower science knowledge, and positive attitudes towards DTC genetic testing for athletic ability were all associated with reportedly changing behavior based solely on genetic test results.

Of the actions taken with the results, 63% of participants in our study reported that they looked up additional information about their results online. It is unclear what they would find on the results but there is the prospect of misinformation. It is also unknown if they would be able to find the limitations of DTC genetic testing. Due to the SNP chip methodology of DTC genetic tests, there are high false positive and false negative rates specifically with rarer pathogenic variants like in the *BRCA* genes (Weedon et al., 2021). This could also lead to self-misdiagnosis, confusion, and emotional burdens (Ayala-Lopez & Nichols, 2020). Specifically, if they are unaware of the limitations of DTC genetic testing, consumers with a positive result could potentially find information on medical management such as increased screening and/or surgical risk-reducing mastectomy for the *BRCA* gene pathogenic variants and want to pursue these options when unnecessary or feel reassured with a negative result despite still being at risk.

In addition, 18% of participants reported that they downloaded their raw DNA and submitted it for additional analysis. While below the 62% who reportedly use third party interpretation in previous research by Wang et al. in 2018, it was the second most common response selected by participants. This difference could potentially be explained since social media platforms such as Reddit were used to recruit participants. It is possible that these individuals can navigate the internet well or are part of online groups that spread the knowledge of third-party interpretation services. This is a concern because 40% of pathogenic or likely pathogenic variants found using third party interpretation on raw DNA data were not confirmed on clinical genetic tests (Tandy-Connor et al., 2018). However, among participants who underwent DTC genetic tests, only 4.41% met with a genetic counselor to discuss their results which is similar to the 3% of participants in the Kaiser Permanente study (Koeller et al., 2017). Of our participants, 13% spoke to another medical professional about their results. Furthermore,

lower science knowledge was significantly associated with behavioral intention for DTC testing of athletic ability. This is troubling since participants state the results would influence their behavior, yet they may be uneducated on the limits of DTC genetic tests and are not turning to genetics experts. This could potentially lead to a lack of understanding and unnecessary medical management (Ayala-Lopez & Nichols, 2020).

This study should be considered in light of certain limitations. In addition to an inability to explain variation in testing uptake, this survey did not specify the underlying type of DTC testing participants underwent or their reasons for undergoing these types of tests. Others, such as the NCGN, PGen, and Kaiser Permanente studies, assessed underlying reasons for testing such as a family history, ancestry, or personal health concerns and reported that ancestry was their main interest in testing, even though the majority also indicated that health information was important for them too (Carroll et al., 2017; Hall et al., 2012; Roberts et al., 2017). The use of an online panel for data collection also presents with issues. There is evidence to suggest that this type of method for data collection might not truly represent a random sample and that the panel is dependent upon the company and their recruitment methods (Kennedy et al., 2016). Future studies should continue to examine the motivations for DTC genetic testing along using an alternative approach to data collection.

In conclusion, this study showed that awareness and interest for DTC genetic testing has increased but uptake remains low. The majority of those who used DTC genetic testing conducted their own research and few met with medical professionals. Around 18% downloaded their raw DNA data and submitted it for additional analysis which is concerning since prior research has shown that there are high false positive rates for this type of analysis. While demographic factors did not explain much of the variation in uptake, this study demonstrated that

males, younger individuals, lower science knowledge, and positive attitudes of DTC genetic testing related to athletic ability increased behavioral intention for these types of results. It seems that these factors, especially attitudes and science knowledge, influence people's perception of the value of DTC genetic test results enough to consider making lifestyle changes. From a public health standpoint, it would be important to find out more about whether general positive attitudes of DTC genetic testing influences uptake and intent to utilize the results of these services particularly among those with lower science knowledge since the results could be misused and misinterpreted. Future research should examine how these factors influence testing uptake and how the results are used with a focus on if medical management has been unnecessarily altered.

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Appendix A: Tables

Table 1

Demographic Information for Tested and Not Tested Groups

Variable	Tested		Not Tested	
	Frequency (n =68)	Percent (12.5%)	Frequency (n = 475)	Percent (87.5%)
Sex				
Male	34	50.0%	225	47.6%
Female	33	48.5%	248	52.4%
Political Views				
Liberal	31	45.6%	137	28.8%
Moderate	20	29.4%	184	38.7%
Conservative	17	25.0%	154	32.4%
Income				
<\$50,000	24	35.3%	225	47.4%
\$50,000-\$99,999	22	32.4%	153	32.2%
>\$100,000	22	32.4%	97	20.4%
Religious Attendance				
Never	18	26.5%	160	33.7%
A few times a year	24	35.3%	168	35.4%
Once a month or more	26	38.2%	138	29.1%
Race				
White	59	86.8%	374	78.7%
Non-White	9	13.2%	101	21.3%
Awareness of GC				
Yes	15	22.1%	58	12.2%
No	53	77.9%	417	87.8%
Variable	Mean	SD	Mean	SD
Age	48.78	18.61	46.17	16.97
Years of Education	15.21	2.43	14.25	2.17
Science Knowledge Scale	3.29	1.26	2.72	1.47

Table 2

Respondents' Answers to Actions Taken with Results of Test

Response	Frequency	Percent ^a
Looked up information on the results of my test online	43	63.20%
Downloaded my raw DNA data and submitted it for additional analysis	12	17.65%
Consulted a physician or other medical professional concerning my results	9	13.24%
Contacted the company that provided the testing for more information	6	8.82%
Had additional genetic testing done	4	5.88%
Met with a genetic counselor	3	4.41%

^aTotal number of responses will be more than 100% because respondents had the option to select more than one answer

Table 3
Binary Regression of Demographic Variables and Science Knowledge on DTC Testing Uptake

Variable	Coefficient	Standard Error	Statistics (p-value)	OR [95% CI]
Liberal ^a	0.689	0.341	0.043*	1.992[1.021-3.887]
Moderate ^a	0.122	0.360	0.735	1.130[0.557-2.289]
Awareness of GC	0.372	0.355	0.294	0.698[0.344-1.382]
Male ^b	0.012	0.300	0.969	1.012[0.562-1.823]
Income	-0.150	0.183	0.412	0.861[0.602-1.231]
White ^c	0.562	0.426	0.187	0.570[0.248-1.314]
Years of Education	-0.108	0.068	0.111	0.898[0.787-1.025]
Age	-0.003	0.009	0.760	0.997[0.979-1.015]
Science Knowledge Scale	-0.181	0.107	0.091	0.835[0.677-1.029]
R ²	0.088			
Adjusted R ²	0.047			

* p < .05

^aReference Group: Conservative

^bReference Group: Female

^cReference Group: Non-White

Table 4***Regression of Intention to Use DTC Sports Results to Change Behavior on Attitudes, Demographic Variables, and Science Knowledge***

Variable	B	95% CI	β	t	Significance (p-value)
Liberal ^a	-0.108	[-0.438-0.221]	-0.025	-0.646	0.518
Moderate ^a	0.046	[-0.265-0.356]	0.011	0.289	0.773
Male ^b	-0.275	[-0.544-(-0.006)]	-0.069	-2.011	0.045*
Income	0.110	[-0.066-0.287]	0.044	1.227	0.22
White ^c	0.194	[-0.143-0.531]	-0.039	-1.132	0.258
Years of Education	0.022	[-0.043-0.087]	0.025	0.666	0.505
Age	-0.023	[-0.031-(-0.014)]	-0.196	-5.180	<0.001***
Science Knowledge Scale	-0.146	[-0.238-(-0.054)]	-0.107	-3.121	0.002**
Attitudes	1.007	[0.893-1.120]	0.582	17.388	<0.001***
R ²	0.449				
Adjusted R ²	0.44				

* p < .05, ** p < .01, *** p < .001

^aReference Group: Conservative

^bReference Group: Female

^cReference Group: Non-White