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Adolescents' Attitudes Towards Direct-to-Consumer Genetic Testing

Master's Thesis

Presented to
The Faculty of the Graduate School of Arts and Sciences
Sarah Lawrence College
Joan H. Marks Graduate Program in Human Genetics

In Partial Fulfillment
of the Requirements for the Degree

Master of Science in Human Genetics

by
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Abstract

The direct-to-consumer (DTC) industry is about a decade old; however, recent years have seen an increase in visibility and uptake due to decreasing prices, television advertisements, and other factors. In the 2018 DNA Day Essay Contest, high school students were asked to research a genetic disorder and to formulate a stance on whether medical professionals should be required for all genetic testing or if consumers should have access to direct-to-consumer testing. Within the 400 coded essays, 80.5% said yes to having a medical professional required and 20.5% said no. Qualitative analysis of the essays revealed the following major themes: benefit of medical providers, consumer knowledge lacking, negative psychological effects, informed consumer, DTC testing companies knowledge lacking, accessibility of DTC testing, accessibility of medical professionals, DTC testing company can use information against the consumer, and insurance companies can use information against the consumer. Although most of the essays agreed to have a medical professional involved in DTC testing, many students cited similar reasons supporting their claims, regardless of their overall opinions of whether or not medical professionals should be involved.

Key Words: Direct-to-consumer testing, adolescents, perspectives, attitudes, genetic testing, ethics

Background

Direct-to-consumer (DTC) genetic testing is any test that does not require written approval from a healthcare professional to be ordered and is marketed directly to consumers. These tests mostly offer information not directly aligned with medical care, such as how likely you are to blush when drinking alcohol or be overweight. In the past these tests were also coupled with risk factors for actual diseases. When scientists and health professionals began to raise concerns the Food and Drug Administration (FDA) stepped in and sent a cease and desist letter to 23andMe, a DTC company, no longer allowing them to return medical results. In 2017 after 23andMe proved test reliability and validity, the FDA allowed them to sell the first DTC test for genetic health risk that tested for 10 health conditions (Allyse, Robinson, Ferber, & Sharp, 2018). The use of DTC genetic testing has expanded rapidly since it emerged and the testing has its benefits and limitations. There have been many suggestions on how current medical procedures can be integrated into this completely different form of delivering health information.

Benefits of Direct-to-Consumer Testing

Arguments in favor of DTC genetic testing include empowerment and accessibility. Even though some experts in the field question test accuracy and clinical significance of DTC genetic tests, individuals have been found to make positive health changes based on their results. In one study, after DTC results ~1/3 of the study participants reported making diet and exercise changes. While the changes could not solely be attributed to the DTC results, the findings still supported the idea that DTC genetic test results can result in positive health changes (Egglestone, Morris, & O'Brien, 2015.; Nielsen et al., 2017). In addition to empowering buyers, DTC tests

also increase accessibility to genetic information. Regulation of what types of tests these companies offer can be seen as “paternalistic” and denying people the right to their own health information (Roberts et al., 2017). Testing through DTC companies is more convenient since the individual does not have to be referred and physically visit a genetics provider or other health professional for genetic testing (Salloum et al., 2018). Some may see this as a big advantage; they don’t have to make an appointment with anyone, meet with someone face-to-face, pay a co-pay, or take time out of their day for a medical appointment. Another benefit of DTC genetic testing is that it raises consumer knowledge about genetics (Leighton et al., 2012) and empowers them that they have a role in decisions about their health. If questions arise from test results, consumers always have the option of contacting a health professional for clarification. Participants in a Sanderson et al. (2017) study looking at the psychological and behavioral impact of returning whole genome sequencing results went on to share their results with relatives, took it upon themselves to gather more information, and 4 out of the 29 participants shared their results with a health care provider. While there were some negative reactions that included disappointment, concern, and wanting more results from the DTC tests, the majority of participants had positive reactions to DTC test results. Some major positive themes included feeling happy, relieved, and glad that they contributed to something bigger than themselves (Sanderson et al., 2017). Therefore, based on these recent studies, the worry of anxiety and concern for the public’s psychological well-being may be exaggerated.

Risks of Direct-to-Consumer Testing

One risk is that DTC genetic testing could provide consumers with information that they never wanted or needed to know. A study in Europe found that 9 out of 24 participants changed

their mind about predictive genetic testing after they learned of the possible positive and negative implications (Wilde, Meiser, Mitchell, & Schofield, 2010). In a similar study, 38% of consumers reported that they did not consider the possibility of unwanted information before purchasing the DTC test, but only 2% actually reported regretting seeking testing (Roberts et al., 2017). In pre-test counseling with a genetic counselor (GC) or other health professional, implications of testing for the patient and family members are discussed (Genetic Counseling, 2008). DTC testing does not offer this same opportunity for anticipatory guidance, which is a fundamental part of genetic counseling. Other opposers of DTC genetic testing argue that misinterpretation of results by consumers and health care providers not trained in genetics could result in rash decisions that negatively affect the patient's health (Roberts et al., 2017). In a study looking at the difference between how consumers interpreted results compared to how genetic counselors interpreted results, a significant difference was found in interpretation of all four presented scenarios. Consumers believed that results from the four scenarios were more useful than GCs did. Eighty-nine percent of GCs could see that a relative risk of 1.45 for colon cancer was a slightly elevated risk for developing disease, while nearly 1/3 of the general population interpreted this as a significant elevation in risk. Consumers may not interpret their results correctly. In three out of the four scenarios given, ~65% of individuals rated the results as easy to understand even though only half of these individuals actually interpreted the results correctly (Leighton, Valverde, & Bernhardt, 2012). Genetics is full of uncertainty, even in a clinical setting working directly with genetics specialists. Direct-to-consumer genetic testing is a lot of information at once without a team there to support the consumer through the process (Oliveri, Renzi, Masiero, & Pravettoni, 2015). Another argument against DTC testing is that consistency between different companies is

lacking. The same sample can be sent to three different companies and they may all return different results (Spencer et al., 2011).

Official Statements on Direct to Consumer Testing

A number of North American societies for genetics professionals, including the National Society of Genetic Counselors (NSGC), the American Society of Human Genetics (ASHG), the International Society of Nurses in Genetics (ISONG), and the American College of Medical Genetics and Genomics (ACMG), have released official statements with regards to DTC testing. These professional organizations all acknowledge potential concerns, such as privacy, misinterpretation of information, and psychological well-being (NSGC, 2019; ASHG, 2015; ISONG, 2017; ACMG, 2015). However, they vary slightly in their positions. ACMG exclusively mentions that DTC companies should only perform tests in CLIA-certified and state-approved labs and that scientific evidence supporting each test should be readily available to explain the purpose of each test (ACMG, 2015). NSGC presents the argument that people have the right to at-home genetic testing (NSGC, 2019). This statement is echoed by ISONG, stating that DTC tests can empower people about their genetic information and could be more accessible in parts of the world with limited testing or strict testing guidelines (ISONG, 2017). An overarching theme between all organizations is that while consumers should have access to DTC genetic testing, medical professionals such as genetic counselors should be made available by the DTC companies to help interpret and deliver results. Other main points are that consumers should have fully informed consent because DTC tests can affect the psychological well-being of consumers (NSGC, 2019; ASHG, 2015; ISONG, 2017; ACMG, 2015).

Health Professionals and Direct-to-Consumer Testing

Health professionals currently have a role in DTC testing. In a 2016 study, at 6 months post return of results 34.9% of participants reported they shared results with a health care provider, 27.3% reported they shared with their primary care physician, 3.0% with someone specializing in genetics, and 15.9% with another medical professional (Carere, Kraft, Kaphingst, Roberts, & Green, 2016). In 2012 a study found five DTC genetic testing companies offered genetic counseling without requiring it, and three offered pre- and post-test counseling through tele-genetic counseling (phone, video chat, or email). The rest of the companies contacted for the study stated that it could be beneficial for their customers to receive genetic counseling (Harris, Kelly, & Wyatt, 2013). One way to understand the draw of DTC testing is to understand the barriers to genetic counseling and testing. Cost, access, fear of discrimination, and not knowing what the results may be are all viable reasons for why individuals may not use the resource of genetic counselors. While there are barriers, an emphasis on benefits such as knowledge for family members and allaying anxiety may help ease apprehension and improve attitudes toward genetic counseling and testing (Gallagher, Bucciarelli, Kavalukas, Baker, & Saunders, 2017).

Adolescents and Genetic Testing

Adolescents historically are individuals between the ages of 13-18, and their attitudes towards genetic testing for hereditary disorders were studied in 2003 by Harel *et al.* (2003). Six hundred and seventy-two students were surveyed in two parts. The first part looked at how much information they knew about three genetic conditions (Tay Sachs, Familial breast cancer, and hypercholesterolemia). The second part looked at their attitudes towards genetic testing for those three conditions. Girls were significantly more willing than boys to be tested for all three

conditions especially Tay Sachs (23% girls vs 13% boys) and hypercholesterolemia (54% girls vs 39% boys). Another trend found was that individuals with a family history of the condition were more motivated to be tested than those without family history. Adolescents may have the capacity to handle their genetic information responsibly (Harel et al., 2003). Exposing adolescents to their health history early on can give them time to process and digest the information. This could also be an invaluable time to share important medical and family history information with them because it is often before they have had or contemplated having children, allowing the information to be useful for reproductive decisions (Boone, 2016). While the Harel et al. (2003) study was one of the first to elicit adolescents' views on genetic testing, it also had limitations. All of the participants were from the same small suburban school in Rhode Island. It did not capture the opinions of students across the United States from different ethnicities and socioeconomic backgrounds. Undergoing genetic testing at any life stage is a major decision. A study by Rew, Mackert, and Bonevac (2011) found that adolescents of ages 14-21 and their parents had very limited knowledge about genetics and genetic testing and felt as though they would be unsure on making decisions based on genetic test results without guidance of some sort. Even though both the adolescents and their parents were found to have very little knowledge of genetics, 45.5% of adolescents said they would go to their parents for information. All groups listed medical professionals and the internet as the top two sources for information. Only the older adolescent (18-21 years old) and parent groups cited psychological themes such as the ability to handle results and burden of knowing as points to consider in decision making. The older adolescent group was also more concerned with credibility of testing. The younger adolescent group (14-17 years old) was more interested in the test itself and the ability to use those results for prevention or preparation (Rew, Mackert, & Bonevac, 2011).

The Need for Adolescent Opinions on Direct-to-Consumer Testing

The thoughts and attitudes of adolescents have been a widely speculated and debated topic, yet little research has been conducted on the subject. Adolescents' attitudes toward DTC testing have not been previously studied. With previous studies examining how adolescents view traditional genetic testing, it is beneficial to learn how adolescents view these new tests and testing companies. This study will examine these attitudes by analyzing essays from the ASHG 2018 International DNA Day essay competition written by high school students from the United States and other countries. From this data we were able to see how adolescents view DTC testing versus genetic testing with a medical professional through qualitative analysis.

Methods

In this study, a mixed-method approach was developed to analyze essays written and submitted by high school students as participants of ASHG'S 2018 International DNA Day Essay contest. The essay prompt to which the students were asked to respond reads as follows:

*“Traditionally, genetic testing for diagnosis or risk of disease has been done in conjunction with medical professionals, such as genetic counselors. These professionals are experts not only in genetics but also in counseling patients and family members about the benefits and potential harms of learning about disease risk. Today, this traditional route is not the only option: direct-to-consumer genetic testing, offered by several companies, does not require a medical professional. The U.S. Food and Drug Administration (FDA) has established a process by which companies can provide predictive testing for certain disorders, in addition to common traits such as straight or wavy hair. **Do you think medical professionals should be required for all genetic testing, or should consumers have direct access to predictive genetic***

testing? In defending your answer, use at least one disorder to explore the implications of involving, and not involving, a medical professional such as a genetic counselor.”

The essays were obtained from the ASHG by the researchers in the Genomic Medicine Institute of Geisinger following the completion of the essay contest. As a part of the entry and submission process, students were informed that their essays might be used for research purposes. This project received an exemption from the Sarah Lawrence College Institutional Review Board (IRB) in January of 2019 and was also exempt from the Geisinger IRB.

All essays were de-identified prior to being received. They were categorized based upon demographic information (grade level, sex, country/state/city) and whether they believe that medical professionals should be required for all genetic testing (Yes), they believe consumers should have direct access to predictive genetic testing (No), did not clearly state an opinion (Unclear) or did not respond to the prompt (No Response). A codebook was developed through inductive analysis with the intention of investigating common themes and reasoning behind the students' opinions if medical professionals should be required for genetic testing or that consumers should have direct access to genetic testing. The final codebook consisted of 30 codes that emerged from the essays. Four coders then utilized the codebook to analyze the essays.

Table I: Codebook created and used to analyze the essays

Code Number	Code	Description
1	Turnaround time is faster with medical professionals	The time it takes to get genetic test results
2	Turnaround time is faster for DTC	Time it takes to get genetic test results, don't need to wait for an appointment
3	Cost of DTC is lower	Cost, out of pocket charge, insurance coverage
4	Cost with a medical professional is	Cost with a medical professional is

	lower	lower, insurance coverage
5	Quality of testing with a medical professional is better than DTC	CLIA, test accuracy, test reliability, confirmatory testing is still needed after DTC, DTC can't be done for prenatal testing/screening
6	Quality of testing without a medical professional is good/sufficient	DTC testing is reliable, results are reliable/accurate
7	Bias- medical professionals would pressure you/ be biased	Pressure to test or not to test by medical professional
8	Medical professionals would not pressure you / be biased	No pressure to test or not to test by a medical professional- own decision
9	Medical Professionals have sufficient knowledge	Medical professionals are well versed in genetic testing and can properly advise consumers
10	Medical professionals do not have sufficient knowledge	Medical professionals are lacking in genetic knowledge
11	Consumer Knowledge Lacking	Consumers ability to accurately interpret test results
12	Consumer Knowledge Sufficient	Consumers can accurately interpret results
13	Consumers will have negative psychological effects from DTC testing	Anxiety, uncertainty about results, anxiety without a medical professional, emotional wellbeing, safety
14	Consumers will have no negative psychological effects from DTC testing	Results from DTC genetic testing will not insue any negative psychological responses to consumer
15	Medical professionals will cause negative psychological effects	Medical professionals will cause negative psychological effects when it comes to testing and effects of testing/results
16	Medical professionals will assuage psychological effects	Medical professionals help with any psychological effects that may arise from results
17	Testing in your home is convenient	Easy, don't have to go anywhere

18	Testing with a medical professional is accessible	Convenience, direct access
19	Testing with a medical professional is not accessible	Patients do not readily have access to medical professionals or insurance
20	Security/Privacy	Insurance using information against patients, security risks (companies have your DNA), invasion of privacy
21	Insurance companies can use information against you	Insurance misuse of patients genetic information against their consent
22	DTC companies can use your information against you	DTC companies misuse of consumer's genetic information against their consent
23	Consumers are protected from their information being used against them	Legislation in place to protect patients genetic information such as GINA
24	Medical professional provides personalized medicine	Rapport building What specific tests you need to get done Human interaction Emotional support
25	DTC is one-size-fits-all (positive)	DTC's one-size-fits-all approach provides all their consumers with the same information therefore no one is left out
26	DTC is one-size-fits-all (negative)	DTC's one-size-fits-all approach overwhelms the consumer with much information by providing them with information that does not pertain to them
27	Medical professionals can help/ are necessary in making decisions to test	Medical professionals aid in planning for future (medically) including presymptomatic testing, family planning
28	Consumers are able to make their own decisions to test	Consumers can plan effectively on their own, including for presymptomatic testing results
29	DTC companies have sufficient knowledge of genetics	CLIA approved labs, accurate tests/results
30	DTC companies do not have sufficient knowledge of genetics	Inaccurate results, not good enough labs, testing too general

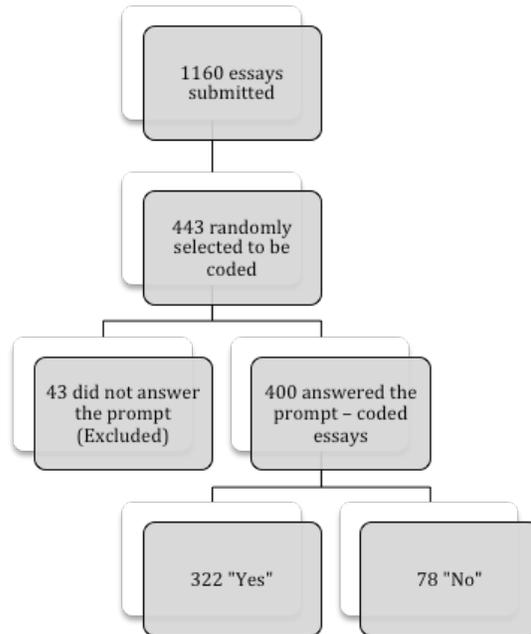


Figure 1: Flowchart of essays coded

Of the 1160 student essays submitted to the 2018 ASHG DNA Day Essay Contest, 443 were randomly selected to be coded by four coders. Of these, 43 did not properly answer the prompt and thus were not coded. Out of the remaining 400 essays that were coded, 322 chose “Yes”, that medical professionals should be required for all genetic testing, while 78 chose “No”, that medical professionals should not be required for all genetic testing (Figure 1).

To ensure consistent use of codes by multiple coders, an inter-rater reliability (IRR) of $\geq 75\%$ must be reached. Each coder coded the same five essays separately. An IRR of 92.22% was established. No codes were removed, added or changed. The 400 essays were then divided evenly amongst the four group members for coding. The essays were hand-coded by group members using Google Sheets.

Upon completion of initial coding, data were downloaded from Google Sheets to Excel Spreadsheets. Included in these data were demographic information (sex, grade level, essay ID),

whether the adolescent responded that medical professionals should be required for all genetic testing (Yes) or if they responded consumers should have direct access to predictive genetic testing (No), and corresponding codes that were in each essay. The 30 codes were then grouped into nine categories: “Benefit of medical providers”, “Consumer knowledge lacking”, “Negative psychological effects”, “Consumers can make decisions on their own (informed consumer)”, “Direct-to-consumer testing company knowledge lacking”, “Accessibility of Direct-to-consumer testing”, “Accessibility of medical professionals”, “Direct-to-consumer testing company can use information against the consumer”, and “Insurance companies can use information against the consumer”. Nine unique chi-squared tests were performed for each category using Excel Formulas and presented in tables. Descriptive statistical analyses were performed on the essays for sex, grade level, Yes versus No response to prompt, and the four class types (Biology, Genetics, Other Science, and Other) using Excel Formulas and presented using graphs and tables. Each code was counted only once per essay for the statistical analyses, regardless of the number of times the was used within an essay. Likewise, for statistical analyses, each category was counted only once per essay, regardless of the number of codes associated with that category appeared in the essay.

Results

Of the 1160 student essays submitted to the 2018 ASHG DNA Day Essay Contest, 443 were randomly selected to be coded. Of these, 43 did not properly answer the prompt and thus were not coded. Out of the remaining 400 essays that were coded, 322 chose “Yes”, that medical professionals should be required for all genetic testing, while 78 chose “No”, that medical professionals should not be required for all genetic testing (Figure 1; Table II).

Table II: Testing choices of the 400 coded essays

Testing Choice	Number of Essays	Percent of Essays Coded
Yes	322	80.5%
No	78	20.5%

The country from where the essay was submitted was also recorded (Table III). Because the vast majority (86%) of the coded essays were submitted from the United States, no further analysis was conducted based on country of origin.

Table III: General demographics of the 400 coded essays

Country	Number of Essays Submitted	Percent of Coded Essays
Austria	1	0%
Bosnia and Herzegovina	2	1%
Canada	7	2%
China	2	1%
India	8	2%
Kazakhstan	2	1%
Martinique	3	1%
Nigeria	1	0%
Philippines	1	0%
Portugal	1	0%

Saudi Arabia	1	0%
Singapore	1	0%
South Korea	1	0%
Turkey	22	6%
Ukraine	1	0%
United Kingdom	2	1%
United States	344	86%
Total	400	100%

Coded essays were also broken down by sex, grade level, and class type (Table IV).

Table IV: General demographics of the 400 coded essays

Demographics	Number of Essays (% of Coded Essays)
Female	262 (66%)
Male	125 (31%)
Prefer Not to Disclose	13 (3%)
9 th Grade	79 (20%)
10 th Grade	101 (25%)
11 th Grade	124 (31%)
12 th Grade	96 (24%)

Genetics Class	49 (12%)
Biology Class	240 (60%)
Other Science Class	75 (19%)
Other	36 (9%)

These three demographic features were further analyzed for how they related to whether respondents said, “Yes” or “No”. The number of respondents who answered “Yes” or “No” based on sex and grade level was similar to the 20% of all respondents who answered “No” (Table V, Table VI). No further analysis was conducted.

Table V: Differences between “Yes” and “No” essays based on sex

Sex	Yes <i>n</i> (% of coded essays)	No <i>n</i> (% of coded essays)
Female	214 (82%)	48 (18%)
Male	97 (78%)	28 (22%)
Prefer Not to Disclose	11 (85%)	2 (15%)

Table VI: Differences between “Yes” and “No” essays based on grade level

Grade Level	Yes <i>n</i> (% of coded essays)	No <i>n</i> (% of coded essays)
9 th	64 (81%)	15 (19%)
10 th	82 (81%)	19 (19%)
11 th	96 (77%)	28 (23%)
12 th	80 (83%)	16 (17%)

The number of respondents who answered “Yes” or “No” based on what type of class in which the essay was written was identified (Table VII).

Table VII: Differences between “Yes” and “No” essays based on class type

Class Type	Yes <i>n</i> (% of coded essays)	No <i>n</i> (% of coded essays)
Genetics	34 (69%)	15 (31%)
Biology	199 (83%)	41 (17%)
Other Science	59 (79%)	16 (21%)
Other	30 (83%)	6 (17%)

A chi-squared test of independence was performed to examine the relation between essays that were written in a genetics class and essays that said medical providers do not need to be involved in DTC genetic testing. The relation between these variables was significant, $\chi^2 (1, N=78) = 3.89, p<.05$. Essays that said that medical providers do not need to be involved in DTC genetic testing were more likely to have been written in a genetics class.

In addition to the basic demographics, each essay was also analyzed based on which major themes were identified. From the 30 codes, 9 major categories were identified based on how often codes appeared to be used together and how often each code was used: “Benefit of medical providers”, “Consumer knowledge lacking”, “Negative psychological effects”, “Consumers can make decisions on their own (informed consumer)”, “Direct-to-consumer testing company knowledge lacking”, “Accessibility of Direct-to-consumer testing”, “Accessibility of medical professionals”, “Direct-to-consumer testing company can use

information against the consumer”, and “Insurance companies can use information against the consumer”. Table VIII describes which codes were grouped into which categories.

Table VIII: Codes that were grouped to establish the 9 major themes

Major Theme	Code(s)
Benefit of medical providers	5. Quality of testing with a medical professional is better than DTC 9. Medical Professionals have sufficient knowledge 16. Medical professionals will assuage psychological effects 18. Testing with a medical professional is accessible 24. Medical professional provides personalized medicine 27. Medical professionals can help/ are necessary in making decisions to test
Consumer knowledge lacking	11. Consumer Knowledge Lacking
Negative psychological effects	13. Consumers will have negative psychological effects from DTC testing
Consumers can make decisions on their own (informed consumer)	12. Consumer Knowledge Sufficient 28. Consumers are able to make their own decisions to test
Direct-to-consumer testing company knowledge lacking	30. DTC companies do not have sufficient knowledge of genetics
Accessibility of direct-to-consumer testing	17. Testing in your home is convenient
Accessibility of medical professionals	19. Testing with a medical professional is not accessible
Direct-to-consumer testing company can use information against the consumer	22. DTC companies can use your information against you
Insurance companies can use information against the consumer	21. Insurance companies can use information against you

Benefit of Medical Providers

The theme of “Benefit of medical providers” was seen in 340 essays and was the most common theme observed overall (85% of 400 essays). All six of the primary codes used in this theme had to do with describing how a medical professional would help during the genetic testing process, such as offering tests with better quality and significance, providing better psychological and emotional support, aiding in direct medical care as it relates to genetic testing results, and providing medical care that is more tailored to an individual. This theme was identified in 28 essays that responded “No” and 312 essays that responded “Yes”. A chi-squared test of independence was performed to examine the relation between essays that had themes of the benefits of medical providers being involved and essays that said medical providers do not need to be involved in DTC genetic testing. The relation between these variables was significant, $\chi^2 (1, N = 340) = 237, p < .01$. Essays that said that medical providers do not need to be required for genetic testing were less likely to mention the benefits of medical professionals.

Consumer Knowledge Lacking

The theme of “Consumer knowledge lacking” was seen in 209 essays (52.25%). This code included essays that said that the average consumer of genetic testing is not knowledgeable enough to accurately interpret genetic test results on their own. This code was identified in 6 essays that responded “No” and 203 essays that responded “Yes”. A chi-squared test of independence was performed to examine the relation between essays that mentioned consumers lacked proper knowledge to correctly interpret DTC genetic testing results and essays that said medical providers do not need to be involved in DTC genetic testing. The relation between these variables was significant, $\chi^2 (1, N = 209) = 186, p < .01$. Essays that said that medical providers

do not need to be required for genetic testing were less likely to mention that consumers lacked proper knowledge.

Negative Psychological Effects

The theme of “Negative psychological effects” was seen in 163 essays (40.75%). This code included essays that said that consumers would have poor psychological outcomes from undergoing direct-to-consumer genetic testing, such as increased anxiety and depression and poor emotional wellbeing in general. This code was identified in 11 essays that responded “No” and 152 essays that responded “Yes”. A chi-squared test of independence was performed to examine the relation between essays that mentioned consumers could have negative psychological side effects and essays that said medical providers do not need to be involved in DTC genetic testing. The relation between these variables was significant, $\chi^2(1, N = 163) = 122$, $p < .01$. Essays that said that medical providers do not need to be required for genetic testing were less likely to mention the possibility that consumers could have negative psychological side effects.

Consumers Can Make Decisions on Their Own (Informed Consumer)

The theme of “Consumers can make decisions on their own (informed consumer)” was seen in 77 essays (19.25%). This theme included essays that said that consumers were able to make an informed decision to undergo genetic testing and had sufficient knowledge to correctly interpret genetic test results. This code was identified in 55 essays that responded “No” and 22 essays that responded “Yes”. A chi-squared test of independence was performed to examine the relation between essays that had themes of consumers being informed enough to make decisions

on their own and essays that said medical providers do not need to be involved in DTC genetic testing. The relation between these variables was significant, $\chi^2 (1, N = 77) = 14.1, p < .01$. Essays that said that medical providers do not need to be required for genetic testing were more likely to mention that consumers are informed enough to make decisions on their own.

Direct-to-Consumer Testing Company Knowledge Lacking

The theme of “Direct-to-consumer testing company knowledge lacking” was seen in 120 essays (30%). This code included essays that said that DTC genetic testing companies did not have sufficient capabilities to correctly identify harmful genetic changes, such as poor quality of testing machines or incorrect algorithms for data analysis. This code was identified in 10 essays that responded “No” and 110 essays that responded “Yes”. A chi-squared test of independence was performed to examine the relation between essays that mentioned DTC genetic testing companies lack sufficient knowledge and essays that said medical providers do not need to be involved in DTC genetic testing. The relation between these variables was significant, $\chi^2 (1, N = 120) = 83.3, p < .01$. Essays that said that medical providers do not need to be required for genetic testing were less likely to mention that DTC genetic testing companies lack sufficient knowledge.

Accessibility of Direct-to-Consumer Testing

The theme of “Accessibility of direct-to-consumer testing” was seen in 99 essays (24.75%). This code included essays that said that direct-to-consumer genetic testing was accessible and convenient. This code was identified in 33 essays that responded “No” and 66 essays that responded “Yes”. A chi-squared test of independence was performed to examine the

relation between essays that mentioned DTC genetic testing is accessible and essays that said medical providers do not need to be involved in DTC genetic testing. The relation between these variables was significant, $\chi^2 (1, N = 99) = 11, p < .01$. Essays that said that medical providers do not need to be required for genetic testing were less likely to mention that DTC genetic testing is accessible.

Accessibility of Medical Professionals

The theme of “Accessibility of medical professionals” was seen in 33 essays. This code included essays that said that medical professionals are not easily accessible. This code was identified in 24 essays that responded “No” and 9 essays that responded “Yes”. A chi-squared test of independence was performed to examine the relation between essays that mentioned that testing with a medical provider is not accessible and essays that said medical providers do not need to be involved in DTC genetic testing. The relation between these variables was significant, $\chi^2 (1, N = 33) = 6.82, p < .01$. Essays that said that medical providers do not need to be required for genetic testing were more likely to mention that testing with a medical provider is not accessible.

Direct-to-Consumer Testing Company Can Use Information Against the Consumer

The theme of “Direct-to-consumer testing company can use information against the consumer” was seen in 37 essays (9.25%). This code included essays that said that DTC genetic testing companies can compromise consumer privacy, such as by selling consumers’ genetic test results to third parties without explicit consent from the consumer. This code was identified in 1 essay that responded “No” and 36 essays that responded “Yes”. A chi-squared test of

independence was performed to examine the relation between essays that mentioned DTC genetic testing companies could use consumers' genetic information against them and essays that said medical providers do not need to be involved in DTC genetic testing. The relation between these variables was significant, $\chi^2 (1, N = 37) = 33.1, p < .01$. Essays that said that medical providers do not need to be required for genetic testing were less likely to mention that DTC genetic testing companies could use consumers' genetic information against them.

Insurance Companies Can Use Information Against the Consumer

The theme of “Insurance companies can use information against the consumer” was seen in 24 essays (6%). This code included essays that said that insurance companies could discriminate against consumers based on their genetic test results, such as by charging more for certain types of insurance. This code was identified in 11 essays that responded “No” and 13 essays that responded “Yes”. A chi-squared test of independence was performed to examine the relation between essays that mentioned insurance companies could use results of genetic testing against people and essays that said medical providers do not need to be involved in DTC genetic testing. The relation between these variables was not significant, $\chi^2 (1, N = 24) = 0.167, p = .68$. Essays that said that medical providers do not need to be required in genetic testing were as likely to mention that insurance companies could use genetic test results against people as essays that said that medical providers need to be involved in genetic testing.

Discussion

There were many statistical correlations found between how students responded to the prompt (“Yes or “No”) and what themes were discussed. We will further discuss possible reasons for why certain themes were discussed and how they may have impacted how a student responded.

Demographics

No significant associations were found between demographic and response other than one class type. Students were more likely to respond “No” if they were in a genetics class. Those students may feel like they know a lot about genetics already and therefore do not need a professional to help them with testing. They may be biased in this way because of their extended knowledge of genetics compared to their peers. Sociodemographic factors also influence awareness and practical knowledge of genetics, (Rahm & Murray, 2017). As stated by Rahm (2017), education levels can affect health literacy; students who were in genetics classes have been exposed to this information and may feel they have higher knowledge of genetics compared to their peers. This difference in education and therefore knowledge may have influenced how those students responded to the prompt and why the association was seen.

Reasons for Involving Medical Professionals

Benefit of Medical Providers

The most common theme among the essays was “Benefit of medical providers”. There was a strong association between the essays that were coded under this theme and also responded “Yes”; the students who mentioned benefits of medical professionals were more likely to argue that medical professional should be involved in genetic testing.

There were a total of six codes used for this theme. One of the codes used for this theme was “Quality of testing with a medical professional is better than Direct-to-consumer”. This theme was seen in essays arguing that genetic testing offered by medical professionals is of better quality and accuracy compared to direct-to-consumer tests. Some of the students questioned the validity of DTC testing by discussing how these tests could be inaccurate compared to testing with a medical professional because of DTC tests not meeting FDA standards or labs not being CLIA-certified. For example, one student said, *“Not all direct-to-consumer genetics testing companies meet the CLIA standards however which weakens the validity of these at home genetics kits”* (Essay 312, Yes: Grade 10, Female, Genetics).

Another reason students argued that the quality of testing is better with a medical professional was because of the lack of genetic variation that can be tested for with DTC testing. Students argued that DTC testing is too broad and cannot identify all that a genetic test with a medical professional can. One student argued, *“However, a negative result doesn't always translate to the fact that the consumer is completely free from cystic fibrosis since most private companies only examine the most common mutations in the CFTR gene that causes cystic fibrosis and don't look at the over 1,000 different mutations”* (Essay 317, Yes: Grade 11, Female, Genetics).

Another code used for this theme was “Medical professionals have sufficient knowledge”. Students discussed that medical professionals are educated and trained in their field and therefore know a lot about genetic testing, which can directly benefit consumers. One student wrote, *“Even more so, the professionals have an extensive education in their field. They can provide accurate and reliable advice”* (Essay 320, Yes: Grade 10, Male, Genetics). Students also discussed how complex genetic testing is and how results can be hard to understand, stating

that, *“Interpretation is technical, complex and require knowledge equipped by some medical professionals”* (Essay 319, Yes: Grade 10, Female, Genetics). Students who used this code in their argument for medical professionals being involved in genetic testing acknowledged that having an educated person involved can be helpful in both understanding and interpreting complex genetic information.

Another code used for this theme was “Medical professionals will assuage negative psychological effects” which was most commonly used when students supported the idea that medical professionals should be involved in genetic testing. Some of the students argued that the presence of a medical professional can help a patient with some of the negative emotions that can arise from genetic testing, saying, *“With results that may hurt the consumer’s state of mind, medical professionals help ease this worry and instill hope”* (Essay 320, Yes: Grade 10, Male, Genetics). Another student reflected on their personal experience with a family member who went through genetic testing, telling, *“For my Grandfather, the help and guidance of a trained medical professional eased the confusion and anxiety about his diagnoses”* (Essay 364, Yes: Grade 12, Female, Genetics). Genetic counselors are trained in counseling and learn ways to handle the psychosocial aspects of genetic testing; these students appear to recognize this and believe it makes these professionals essential to the testing process. Some students also believed that testing with a medical professional is accessible and not hard to come by, as another code that fell under this theme was “Testing with a medical professional is accessible”. Students argued that access to a medical professional is not an obstacle keeping people from being able to test with one.

Another code used in this theme was “Medical professionals provide personalized medicine”. Some of the students believed that the personal aspect of seeing a medical

professional in person is helpful to people in helping with their emotion well-being. For instance, a student wrote, *“Also, with medical professionals, there is an essence of a human connection. The professionals are trying to help the consumer and in this, they are creating an aura of friendliness. This can impact a clear majority of consumers and create a more accepting, calming environment”* (Essay 320, Yes: Grade 10, Male, Genetics). They also stressed the importance of what information you miss out on when getting DTC testing; aspects such as family history and implications for family planning which are included when you test with a medical professional. As stated by one student, *“Professionals in the medical field provide preventive, promotional or rehabilitative health care services in an orderly way to people, families or communities. They help to identify families at possible risk of a genetic disorder, gather and analyze family history and inheritance patterns, calculate risks of recurrence, and provide information about genetic testing and related procedures...Unlike DTC genetic testing, professionals can have face to face discussions with patients to help them understand their test results. They can give more personal and specific information regarding a disease rather than a company that has no personal connection to a patient”* (Essay 24, Yes: Grade 12, Male, Biology).

Another code used in this theme was “Medical professionals can help/are necessary in making decisions to test”. Students used this code in support of medical professionals and how they can help patients chose the correct test, guide them through possible treatment options, and provide them with the most precise information. One student described this by saying, *“When consulting with genetic counselors, they would inspect the patient’s family history in order to provide the most accurate genetic analysis”* (Essay 318, Yes: Grade 10, Female, Genetics). These students recognize the impact that medical professionals can have on genetic testing and

argue that DTC testing leaves a lot of information out. Implications of testing for the patient and family members are discussed in pre-test counseling with a genetic counselor or other health professional (Genetic Counseling, 2008). This shows that those students who believe medical professionals are beneficial also think they should be involved in testing, whereas those students who do not think medical professionals should be involved with genetic testing failed to mention these types of benefits of having one.

Consumer Knowledge Lacking

Another main theme seen in the essays was the idea of consumer knowledge and how well a consumer can interpret the results of genetic testing. The code “Consumer knowledge lacking” was used in essays that discussed how the average consumer is not knowledgeable enough to accurately interpret the results of genetic testing on their own. Essays that argued against medical professionals were less likely to mention that consumers lack the knowledge needed to interpret genetic test results.

Students who mentioned the lack of consumer knowledge discussed how it can negatively affect a patient, saying, *“All this is very complicated for the average consumer who is unlikely to have the knowledge and expertise required to accurately interpret the tests and to understand the minor nuances of the test results and what it means for him or her”* (Essay 349, Yes: Grade 11, Female, Biology). Students pointed out how consumers may not be able to interpret their results and therefore may not be able to use any of the information, potentially causing negative effects for the consumer. Students also discussed how having a degree or an education related to this field makes someone knowledgeable and how important it is to understand genetic testing and the potential impacts it can have for someone. One student

described this by saying, *“Without a medical education, people cannot properly evaluate their genome and its potential life-changing effects”* (Essay 392, Yes: Grade 9, Female, Biology).

These students may have been thinking of their own personal experiences if they or someone close to them had genetic testing and the results were difficult to understand. They may also be predicting how well a consumer could accurately interpret results and believe that a medical professional could be beneficial in that process. It has been discussed that the misinterpretation of results by consumers and health care providers not trained in genetics could result in rash decisions that negatively affect the patient’s health (Roberts et al., 2017).

Negative Psychological Effects

The theme of “Negative psychological effects” was seen in a number of essays. Students who mentioned consumers could have negative psychological effects from DTC genetic testing were more likely to respond with “Yes”. Those who argued that side effects were rare were also less likely to mention the possibility of negative psychological effects from DTC genetic testing.

Some essays mentioned how not being able to interpret the results of a genetic test could alone be a source of negative emotions, through stating, *“Positive DTC genetic test results can lead to anxiety and stress in consumers who are unable to interpret all of the risks in perspective”* (Essay 349, Yes: Grade 11, Female, Biology). Some students brought up the idea of DTC testing being inaccurate and how that could negatively affect a consumer, *“Furthermore, inaccurate genetic information may cause individuals to experience episodes of anxiety, shock, and depression”* (Essay 407, Yes: Grade 11, Female, Science). The accuracy and validity of DTC genetic testing was questioned by an abundance of students but some used this as an example of how DTC genetic testing could cause negative psychological effects. Other students

also mentioned how medical professionals could be of help to consumers when it comes to the negative psychological effects from genetic testing, by saying, *“Everyone deals with bad news differently, but it could be very detrimental to a person's mental health to find something like this out without a counselor to guide them in how to cope and what precautions can be take to live their best life”* (Essay 402, Yes: Grade 11, Male, Biology). The quote above helps to explain one of the reasons why this code was used more in essays that responded with “Yes”; if students believe that DTC testing can cause negative psychological effects, they may also come to the conclusion that this could be prevented by the addition of a medical professional. As shown by Matloff (2019), even trained genetic counselors themselves can have negative psychological effects from DTC testing, *“Calm, cold panic sets in...Next, the implications for my daughter, sister, cousins, and their children flashed through my mind”* (Matloff, 2019). These students accurately pointed out what effects DTC testing can have and what may help assuage these negative emotions.

Direct-to-Consumer Testing Company Knowledge Lacking

The theme “Direct to Consumer Testing Company Knowledge Lacking” was associated with essays that responded “Yes”; those who said medical professionals should be involved in genetic testing were more likely to mention the lack of knowledge of DTC genetic testing companies. Students who responded with “No” were significantly less likely to use this theme in their essays. Most of the students who discussed this theme focused on the lack of accurate results and the genetic limitations of DTC genetic tests with one student writing, *“The specific third-party company failed to acknowledge hundreds of mutations of non-Ashkenazi Jews and thus gave false scores for breast cancer risk due to their lack of information on many of the*

known causative mutations” (Essay 321, Yes: Grade 10, Male, Genetics). Another student specifically compared the testing quality to that used by professionals, “*Medical professionals also have access to the highest quality equipment, giving them the best results. DTC-GT companies do not have equipment of the same caliber, and therefore receive varied results*” (Essay 381, Yes: Grade 12, Female, Biology).

Accessibility of Direct-to-Consumer Testing

The theme of accessibility of DTC testing was mentioned in essays that described how DTC genetic testing is convenient, easily accessible, and less time-consuming than testing with a medical professional. Our data showed a significant relationship between essays that mentioned this theme and those who responded with “No”. Essays that said medical professionals should not be required for genetic testing were however less likely to discuss how DTC testing is accessible.

The main argument for the accessibility of DTC testing was the fact that a consumer can test in their own home as explained by a student who wrote, “*these tests are conveniently shipped straight to your doorstep, most commonly as ‘at-home DNA kits’*” (Essay 324, No: Grade 10, Female, Genetics). Students recognized how DTC testing is easily accessible and convenient for a consumer. The fact that it was mentioned more in essays that said that medical professionals should be involved in genetic testing may be explained by these students being aware of this accessibility component but not thinking it is important enough to take the place of testing with a medical professional.

Direct-to-Consumer Testing Company Can Use Information Against the Consumer

This theme was seen in essays that discussed possible ways that DTC testing companies can violate consumer privacy. Students who argued that medical professionals should be involved in testing were much more likely to discuss how DTC testing companies could use information against the consumer. Those who did not support medical professionals being involved in genetic testing were less likely to discuss this theme.

Students who discussed this theme mainly focused on the possibility of DTC companies selling consumer information to third parties without the patient's consent, "*The desire for medical privacy can also backfire, as there have been incidents of companies that offer genetic testing, like 23andMe, selling user data to outside parties for profit*" (Essay 369, Yes: Grade 12, Female, Genetics) Essays also discussed how patient privacy is not guaranteed with DTC genetic testing and that using these companies puts consumers at risk of their privacy being violated. These students believe that testing with a medical professional ensures more privacy and therefore is less risky than DTC genetic testing.

Reasons to Not Involve Medical Professionals

Consumers Can Make Decisions on Their Own (Informed Consumer)

The theme of "Consumers can make decisions on their own (informed consumer)" was used by students who argued against medical professionals being involved in genetic testing.

Essays that were coded under this theme stressed the importance of autonomy. Most students discussed how consumers should have the ability to choose genetic testing on their own and that they are capable of doing so, "*Granting the person autonomy towards his own body allows for independent decision-making and thus allow him to attain the happiness he desires, because he is as informed as he intends to be*" (Essay 355, No: Grade 10, Male, Science). While

some students acknowledged that a medical professional can be helpful, the importance of autonomy seemed to outweigh this for the essays that were coded for this theme and believed that medical professionals should not be required for DTC genetic testing. One student described this as, *“While professional genetic counseling certainly provides numerous compelling benefits for patients and is certainly recommended to be sought, to require it as a necessity for testing would be an infringement upon the autonomy of the individual to exercise his own informed, conscious decision whether or not to seek counseling”* (Essay 366, No: Grade 12, Male, Genetics). Patient autonomy was a theme among these essays and adding the requirement of a medical professional for genetic testing may seem like a violation of that autonomy to some people. This may be one aspect to why there was a significant association among the essays that mentioned how consumers can make their own informed decisions and those that did not think medical professionals should be required for genetic testing.

Accessibility of Medical Professionals

This theme was seen primarily in essays that described how medical professionals are not easily accessible. Our data showed a strong association between essays that mentioned this theme and those who responded “No”; those who did not think medical professionals should be required for testing were more likely to mention that medical providers are not easily accessible. Students discussed that accessibility to medical professionals can be difficult for many reasons, including limitation of healthcare in certain countries, living far away from a genetic counselor, and the difficulties that come along with making an appointment with a medical professional even if location is not an issue. One student wrote, *“Genetic testing has long been a difficult thing to access, requiring an individual to seek out the aid of a genetic counselor, oftentimes*

hard to get an appointment with” (Essay 379, No: Grade 12, Female, Other). Students who discussed this theme may be inclined to favor DTC testing since it is thought to be convenient for consumers. This may explain the association that was found.

Reasons Both For and Against Involving Medical Professionals

Insurance Companies Can Use Information Against the Consumer

This theme was seen across essays that discussed how insurance companies could use information against consumers by discriminating against people as a result of genetic testing. This theme was mentioned roughly evenly between the two arguments. Our data showed no significant relationship between essays that discussed insurance companies being able to use information from genetic testing against the consumer and how they responded (“Yes” or “No”).

Students discussed that insurance companies could use information against consumers by charging more for insurance or by denying someone insurance based on the results of a genetic test, *“If you choose to see a genetic counselor, your insurance company is always involved and your results can constrain you from being able to purchase long term insurance in the future based on the results of a genetic test”* (Essay 387, No: Grade 9, Female, Biology). This theme was not shown to affect whether or not students thought medical professionals should be involved in genetic testing.

Study Limitations

This study was conducted using essays from the ASHG DNA Day essay contest and had a few limitations. First of all, the demographics of the sample were not evenly distributed among sex and country of submission. The majority of essays were submitted by female students, which may have influenced our results and contributed to certain bias in how students answered the

prompt. The essays were also submitted from 17 different countries but were not represented equally, since a majority of the essays were submitted by students in the United States.

Therefore, the results are skewed towards the opinions of students in the U.S. and do not accurately represent the opinions of adolescents in all of the countries of submission. We included essays submitted by students in non-U.S. countries since DTC testing is available to people outside of the U.S.

Another limitation is that this study was conducted using a sub-set of essays; a random sample of 400 essays were used for analysis out of the 1,160 that were submitted. It is possible that additional themes may be present in essays that were not reviewed, and therefore our study may not represent all of the themes that were discussed in the essays.

Another limitation is that we are not aware of how the essays were submitted – if the students chose to write an essay for the contest on their own or if this was a requirement of the school or of a teacher. The submitted essay could be a representation of an assigned argument (for or against involvement of professionals) rather than the adolescent’s actual opinion on the subject. The student’s knowledge about genetic information is also a limitation. Besides the students that were in genetics or biology classes, we do not know how much knowledge they have about genetics or how much exposure to genetic testing they have. DTC testing is advertised on television, but we do not know how much exposure they had to advertisements or if they discuss it with their parents or peers. Any lack of exposure or knowledge may have affected how they responded. The essays used for analysis were only those who had a clear ‘Yes’ or ‘No’ answer; essays that did not have a clear stance were not included, which may have limited the amount of different themes seen throughout the essays.

Research Recommendations

There are a few research recommendations to further investigate adolescent opinions on DTC genetic testing. Further analysis to include more essays or the entire sample may improve upon how well this study represents adolescent opinions on DTC genetic testing. This study may be re-conducted using a different format such as a voluntary survey or direct interview as opposed to an essay contest. This may overcome the limitation that the submissions do not accurately represent adolescent opinions if the submissions were forced or for an assignment.

Practice Implications

We saw a number of different adolescent opinions on DTC genetic testing while analyzing the data for this study. It may be useful for regulation and consenting purposes to take these opinions into account when it comes to genetic testing. Some of the essays that were analyzed did not show a clear understanding of genetics or genetic testing. This may be improved upon by better and more thorough pre-test counseling and education provided by both medical professionals and DTC genetic testing companies, such as more information on company websites or pre-tests to assess patient knowledge before testing.

Conclusion

A majority of adolescents believed that medical professionals should be required for genetic testing. Despite the fact that students expressed differing opinions on whether medical professions should be required for genetic testing or consumers should have direct access to their genetic information through the use of DTC testing, most students cited nine general themes to support their claim. Students were able to make connections to their own lives and values and

use real-world examples in defense of their stance. However, there were instances in which it became clear that students did not fully understand many concepts, such as how genetic tests are performed, how insurance coverage works, what genetic testing protocol entails, or a basic understanding of the role genetics plays in disease. Their misunderstanding of these concepts highlights the importance of medical professionals being involved in the genetic testing process to guide and explain these concepts to the general population. Although DTC genetic testing allows for cheaper and more readily accessible genetic information, most consumers do not have the background knowledge to correctly interpret or act upon results from these types of tests. In order to further understand the general population's issues with involving medical professionals in genetic testing, adolescents' perspective must be considered in future discussions.

Conflict of Interest

J. Fitzpatrick Doyle, Carli Andrews, Katherine Orr, and Rebekah Hutchins declare that they have no conflicts of interest.

Reference List

- ACMG Board of Directors. (2015). Direct-to-consumer genetic testing: a revised position statement of the American College of Medical Genetics and Genomics. *Genetics in Medicine*. <https://doi.org/10.1038/gim.2015.190>
- Allyse, M. A., Robinson, D. H., Ferber, M. J., & Sharp, R. R. (2018). Direct-to-Consumer Testing 2.0: Emerging Models of Direct-to-Consumer Genetic Testing. <https://doi.org/10.1016/j.mayocp.2017.11.001>
- ASHG Position Statement Provides Guidance for Genetic Testing in Children and Adolescents. (2015). Retrieved May 24, 2018, from <https://www.genomeweb.com/molecular-diagnostics/ashg-position-statement-provides-guidance-genetic-testing-children-and#.WvsR89MvzR2>
- Boone, P. M. (2016). Adolescents, Family History, and Inherited Disease Risk: An Opportunity. *Pediatrics*, 138(2), e20160579. <https://doi.org/10.1542/peds.2016-0579>
- Carere, D. A., Kraft, P., Kaphingst, K. A., Roberts, J. S., & Green, R. C. (2016). Consumers report lower confidence in their genetics knowledge following direct-to-consumer personal genomic testing. *Genetics in Medicine : Official Journal of the American College of Medical Genetics*, 18(1), 65–72. <https://doi.org/10.1038/gim.2015.34>
- Carere, D. A., VanderWeele, T., Moreno, T. A., Mountain, J. L., Roberts, J. S., Kraft, P., ... PGen Study Group, for the Pg. S. (2015). The impact of direct-to-consumer personal genomic testing on perceived risk of breast, prostate, colorectal, and lung cancer: findings from the PGen study. *BMC Medical Genomics*, 8, 63. <https://doi.org/10.1186/s12920-015-0140-y>
- Carmody, D., Lindauer, K. L., & Naylor, R. N. (2015). Adolescent non-adherence reveals a genetic cause for diabetes. *Diabetic Medicine : A Journal of the British Diabetic Association*, 32(6), e20-3. <https://doi.org/10.1111/dme.12669>
- Egglestone, C., Morris, A., & O'Brien, A. (n.d.). Effect of Direct-to-Consumer Genetic Tests on Health Behaviour and Anxiety: A Survey of Consumers and Potential Consumers. <https://doi.org/10.1007/s10897-013-9582-6>
- Fanos, Joanna H. (1997). Developmental Tasks of Childhood and Adolescence: Implications for Genetic Testing. *American Journal of Medical Genetics*, 71:22–28.
- Gallagher, T. M., Bucciarelli, M., Kavalukas, S. L., Baker, M. J., & Saunders, B. D. (2017). ATTITUDES TOWARD GENETIC COUNSELING AND TESTING IN PATIENTS WITH INHERITED ENDOCRINOPATHIES. *ENDOCRINE PRACTICE*, 23(9). <https://doi.org/10.4158/EP171875.OR>
- Genetic counseling: an indispensable step in the genetic testing process. (2008). *Journal of oncology practice*, 4(2), 96–98. doi:10.1200/JOP.0827002
- Godino, L., Turchetti, D., Jackson, L., Hennessy, C., & Skirton, H. (2016). Impact of presymptomatic genetic testing on young adults: a systematic review. *European Journal of Human Genetics : EJHG*, 24(4), 496–503. <https://doi.org/10.1038/ejhg.2015.153>
- Gollust, S. E., Gray, S. W., Carere, D. A., Koenig, B. A., Lehmann, L. S., McGuire, A. L., ... Roberts, J. S. (2017). Consumer Perspectives on Access to Direct-to-Consumer Genetic Testing: Role of Demographic Factors and the Testing Experience. *The Milbank Quarterly*, 95(2), 291–318. <https://doi.org/10.1111/1468-0009.12262>
- Harel, A., Abuelo, D., & Kazura, A. (2003). Adolescents and genetic testing: what do they think about it? *Journal of Adolescent Health*, 33(6), 489–494. <https://doi.org/10.1016/S1054->

139X(03)00135-6

- Harris, A., Kelly, S. E., & Wyatt, S. (2013). Counseling customers: emerging roles for genetic counselors in the direct-to-consumer genetic testing market. *Journal of Genetic Counseling*, 22(2), 277–288. <https://doi.org/10.1007/s10897-012-9548-0>
- International Society of Nurses in Genetics Position Statement: Direct-to-Consumer Genetic/Genomic Testing (DTC-GT). (2017). Retrieved from [https://www.isong.org/resources/Documents/PS_DTC GT Position Statement_Approved October 2017.pdf](https://www.isong.org/resources/Documents/PS_DTC_GT_Position_Statement_Approved_October_2017.pdf)
- Landry, L., Nielsen, D. E., Carere, D. A., Roberts, J. S., Green, R. C., & PGen Study Group, the Pg. S. (2017). Racial minority group interest in direct-to-consumer genetic testing: findings from the PGen study. *Journal of Community Genetics*, 8(4), 293–301. <https://doi.org/10.1007/s12687-017-0325-5>
- Leighton, J. W., Valverde, K., & Bernhardt, B. A. (2012). The General Public's Understanding and Perception of Direct-to-Consumer Genetic Test Results. *Public Health Genomics*, 15, 11–21. <https://doi.org/10.1159/000327159>
- Matloff, E. (2019, February 12). I Had Lynch Syndrome For 30 Hours. Retrieved from <https://www.forbes.com/sites/ellenmatloff/2019/02/12/i-had-lynch-syndrome-for-30-hours-2/#2721f9262567>
- National Society of Genetic Counselors : Genetic Counselors - By Specialty. Retrieved April 10, 2019, from <https://www.nsgc.org/page/specialty-areas>
- National Society of Genetic Counselors : Position Statements : Direct Access to Genetic Testing. (2015). Retrieved May 24, 2018, from <https://www.nsgc.org/p/bl/et/blogaid=370>
- Nielsen, D. E., Carere, D. A., Wang, C., Roberts, J. S., Green, R. C., & PGen Study Group, for the Pg. S. (2017). Diet and exercise changes following direct-to-consumer personal genomic testing. *BMC Medical Genomics*, 10(1), 24. <https://doi.org/10.1186/s12920-017-0258-1>
- Niemiec, E., Kalokairinou, L., & Howard, H. C. (2017). Current ethical and legal issues in health-related direct-to-consumer genetic testing. *Personalized Medicine*, 14(5), 433–445. <https://doi.org/10.2217/pme-2017-0029>
- Oliveri, S., Renzi, C., Masiero, M., & Pravettoni, G. (2015). Living at Risk: Factors That Affect the Experience of Direct-to-Consumer Genetic Testing. *Mayo Clinic Proceedings*, 90(10), 1323–1326. <https://doi.org/10.1016/j.mayocp.2015.06.014>
- Rahm, A. K., & Murray, M. F. (2017). Chapter 20 - Educational Issues and Strategies for Genomic Medicine: For the Public and for Providers. In *Genomic and Precision Medicine* (3rd ed., pp. 299-311). Elsevier. doi:<https://doi.org/10.1016/B978-0-12-800681-8.00020-7>
- Rew, L., Mackert, M., & Bonevac, D. (2010). Cool, but is it Credible? Adolescents' and Parents' Approaches to Genetic Testing. *Western Journal of Nursing Research*, 32(5), 610–627. <http://doi.org/10.1177/0193945909360781>
- Roberts, J. S., Gornick, M. C., Carere, D. A., Uhlmann, W. R., Ruffin, M. T., & Green, R. C. (2017). Direct-to-Consumer Genetic Testing: User Motivations, Decision Making, and Perceived Utility of Results. *Public Health Genomics*, 20, 36–45. <https://doi.org/10.1159/000455006>
- Salloum, R. G., George, T. J., Silver, N., Markham, M.-J., Hall, J. M., Guo, Y., ... Shenkman, E. A. (2018). Rural-urban and racial-ethnic differences in awareness of direct-to-consumer genetic testing. *BMC Public Health*, 18(1), 277. <https://doi.org/10.1186/s12889-018->

- Sanderson, S. C., Linderman, M. D., Suckiel, S. A., Zinberg, R., Wasserstein, M., Kasarskis, A., ... Schadt, E. E. (2017). Psychological and behavioural impact of returning personal results from whole-genome sequencing: the HealthSeq project. *European Journal of Human Genetics : EJHG*, 25(3), 280–292. <https://doi.org/10.1038/ejhg.2016.178>
- Sijmons, R. H., Van Langen, I. M., & Sijmons, J. G. (2011). A Clinical Perspective on Ethical Issues in Genetic Testing. *Accountability in Research*, 18, 148–162. <https://doi.org/10.1080/08989621.2011.575033>
- Spencer, D. H., Lockwood, C., Topol, E., Evans, J. P., Green, R. C., Mansfield, E., & Tezak, Z. (2011). Direct-to-consumer genetic testing: reliable or risky? *Clinical Chemistry*, 57(12), 1641–1644. <https://doi.org/10.1373/clinchem.2011.167197>
- Tabor, H. K., & Kelley, M. (2009). Challenges in the use of direct-to-consumer personal genome testing in children. *The American Journal of Bioethics : AJOB*, 9(6–7), 32–34. <https://doi.org/10.1080/15265160902893916>
- Vayena, E. (2015). Direct-to-consumer genomics on the scales of autonomy. *Journal of Medical Ethics*, 41(4), 310–314. <https://doi.org/10.1136/medethics-2014-102026>
- Wilde, A., Meiser, B., Mitchell, P. B., & Schofield, P. R. (2010). Public interest in predictive genetic testing, including direct-to-consumer testing, for susceptibility to major depression: preliminary findings. *European Journal of Human Genetics : EJHG*, 18(1), 47–51. <https://doi.org/10.1038/ejhg.2009.138>