

Personal Risk Analysis of Direct-to-Consumer Genetic Testing

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On my honor as a University Student, I have neither given nor received
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Introduction to the Risks of DTC-GT Services:

Imagine that your grandmother has been diagnosed with Alzheimer's. You see the effects on your family and your relationship with her. She is losing her memories slowly, especially the memories she has of you. You are devastated by this deterioration and are having a hard time dealing with these emotions. Your dad is debating getting a full-time nurse but is having to figure this out fast and determine how much money he has available. He is constantly looking at all of his options but what if there was a way to prepare yourself and your family for this? That is what is being marketed with direct-to-consumer genetic testing (DTC-GT), a way to know your chances of acquiring a disease and therefore providing time for you and your family to plan accordingly.

DTC-GT are tests that are performed on a person's DNA, have no association with the healthcare system, and provides information such as a person's ancestry, food intolerances, disease risk percentage, and much more (Badalato et al., 2017; CCMG Ethics and Public Policy Committee et al., 2012; Oliveri et al., 2016; Williamson & Duncan, 2002). The only caveat is that not everyone understands the personal risks that they are taking when performing these tests. These risks include a person's genetic information being made available to insurance companies and employers, the disease risks percentage not being completely accurate and therefore a person receiving misinformation, and also a person not fully understanding their results leading them to make unnecessary lifestyle changes. (Bloss et al., 2010; Kutz, 2010). Therefore, the purpose of this STS paper is to determine what personal risks a person takes when partaking in DTC-GT services. The framework risk analysis by Ulrich Beck is utilized in order to discern what these risks are.

Research Question and Approach to Assessing the Risks of DTC-GT Services:

The goal of this STS paper is to answer the following question: what personal elements of risk are associated with DTC-GT services? In order to answer this question, two methods are used: documentary research and discourse analysis. Documentary research is utilized by analyzing scientific research papers and news articles. The papers include information about DTC-GT services in regards to cost decrease, validity of tests, genomic literacy (the ability of a person to interpret the results), and privacy regulations. The research focuses on two DTC-GT companies, 23andMe and Ancestry.com. In order to evaluate these companies, the terms and conditions, privacy regulations, selling of data, and one-on-one consultation with doctors or a person at the company regarding results are to be evaluated. Discourse analysis is applied by examining YouTube videos of 23andMe's advertisements. The advertisements include consumers, who had favorable experience with the service, discussing their experience and the emotions that they felt. Words and phrases such as "scared, relieved, happy, overwhelmed, peace of mind, and benefits" are all carefully listened for in order to determine how 23andMe is advertising the benefits of its services to potential consumers. The information gathered is then analyzed in order to determine if 23andMe actually provides those services and if consumers have a similar end experience to what the commercial advertise.

Background Information on DTC-GT Services:

Direct-to-consumer genetic testing (DTC-GT) services conduct analysis on a person's DNA in order to convey a broad range of information such as a person's ancestry and risk of acquiring certain diseases. (Badalato et al., 2017). The information is gathered by looking at single nucleotide polymorphisms (SNPs) (Sboner et al., 2011). SNPs are mutations that occur in greater than one percent of the tested population (Caulfield & McGuire, 2012).

The identification of SNPs has greatly helped with the expansion of DTC-GT services because they allow for quick analysis of a person's genome. Each SNP, that is tested for, is related to a piece of information about a person. For example, it is possible to determine that a certain SNP occurs in people of British heritage at a higher rate than people from anywhere else. Therefore, if a person has that SNP then they likely have some British heritage in their family, thus allowing for ancestry analysis (Zettler et al., 2014). The analysis of SNPs has also expanded to provide information on disease risk, paternity, fetal gender, drug response, preconception screening, and food intolerances (CCMG Ethics and Public Policy Committee et al., 2012; Oliveri et al., 2016).

The expansion and advancements of SNPs has led to a reduction in cost. When 23andMe, a DTC-GT for ancestry, was first created in 2007, its services cost consumers 999 dollars (Roberts & Ostergren, 2013). However, after 13 years, the cost has reduced to 99 dollars for consumers (Roberts & Ostergren, 2013). This reduction in cost and increase in information has led to the creation and expansion of many DTC-GT companies. 23andMe expanded from ancestry to also providing a personal genome service which gives a risk percentage regarding acquiring a certain disease (Annas & Elias, 2014). Ancestry.com is following a similar business progression to 23andMe by also providing risk percentages for certain diseases. 24Genetics, Atlas Biomed, Easy DNA, and Mapmygenome are all newer companies that have appeared and conduct similar business to 23andMe in terms of disease risk percentage (Markets, 2019).

With the new companies and lower cost, comes more customers. In 2018, the DTC-GT market in the United States was 299.4 million (*U.S. Direct-to-Consumer Genetic Testing Market to Hit \$890 Million by 2025*, 2019). This market is projected to be greater than 890 million by 2025 (*U.S. Direct-to-Consumer Genetic Testing Market to Hit \$890 Million by 2025*, 2019).

With this projected increase in customers, comes the need for more clarity in regard to what risks a person takes when they perform these tests. In a study done with 3,640 customers of DTC-GT services, approximately half had concerns about their privacy, knowing how to feel about risk percentages provided, and learning what those risk percentages are (Bloss et al., 2010). However, analyzing the risks associated with DTC-GT is not easy due to not all services being the same. Some provide different amenities, have different privacy regulations, and also use different SNP markers in order to evaluate a person's DNA. In a study done by the United States Government Accountability Office, it was found that when one person's DNA was tested by four DTC-GT services, the disease risk results varied (Kutz, 2010). The variation in results illustrates that there is a large amount of variability in the disease risk percentage process and that consumers should be aware that the results they receive from one service will have inaccuracies.

Risk Analysis by Ulrich Beck:

Risk analysis, as stated by Ulrich Beck in his book a *Critical Introduction to Rick Society*, is used as a framework to evaluate the personal risks a person takes when conducting DTC-GT services (Mythen, 2004). Ulrich Beck's risk analysis incorporates the concepts of risks that have arisen due to modern society (Sørensen, 2018). The risks are called 'man-made disasters', or 'new-risks', and are different from previous risks, such a building catching on fire, because they are hard for insurance companies to insure for due to the difficulty in pricing them (Sørensen, 2018). The difficulty in pricing arises because the consequences of these 'new risks' are hard to calculate and often involve "global, frequently irreparable damage" (Sørensen, 2018).

Risk Analysis has been utilized to understand the risk of drugs with youth and also drug prevention policies in the United Kingdom (Jones, 2004). The paper, that describes this analysis of drug use, hopes to understand the effects of government policies on drug use in regard to

expelling the use of drugs. In particular, the paper hopes to understand the direction that the policies should go towards and the unintended consequences the current policy might be having. In particular, looking at anxiety felt by parents and ‘manufactured risks’, which are risks created by governmental policies (Jones, 2004). The paper provides a process for analyzing current new risks, in regards to health, in order to see the potential effects that the risks could have on society. The analysis process is applicable for the analysis of DTC-GT services, and the personal risks that it induces, because it provides a method to analyze the effects DTC-GT services are having on society and thus the personal risks people take when performing the services.

Risk Analysis is believed to be a good tool for analysis because it helps to remove the emotional anxiety behind risks (Jones, 2004). Talking about risks has always led people to be more anxious about them (Elliott, 2002). Therefore, by utilizing risk analysis, the anxiety of the risks associated with DTC-GT services can be removed and conclusions, unbiased by anxiety, can be drawn. Additionally, Ulrich Beck states that the “new risks” that people take are not solely going to be affected by a few people but rather a large population, and in some cases the whole world (Jones, 2004). Therefore, risk analysis provides the ability to understand the personal risks a person takes when conducting DTC-GT services and also the affected that these risks could have on the entire society, such as employment policy changes to make disease risk percentages mandatory.

The paper on drug use in the United Kingdom also discussed objections to risk analysis. One of their major complaints was that the theory is over-stretched. Critics argue that new risks are dispelled over time and Ulrich Beck’s risk analysis is therefore not helpful because it does not look at those risks over a long period of time (Jones, 2004). Another criticism is that risk

analysis is not able to be utilized to give guidance to what the government should do to adjust the policies put in place or if there should be a change in direction (Jones, 2004).

However, even with these critics, risk analysis is a good framework for analyzing the risks of DTC-GT. Risk analysis provides the ability to gather information about risks that affect the general public and not just a single person. Additionally, the purpose of this paper is to discuss and identify the risks seen from these services and not determine what governmental policies will need to be put in place.

The Personal Risks of DTC-GT Services:

Direct to consumer genetic testing (DTC-GT) fits the categories of a ‘new risk’ by Ulrich Becks standards. Therefore, consumers take on personal risks when they utilize these services. These personal risks can be illustrated by the three main criteria of a new risk: uninsurable, symbolic detoxification, and organized irresponsibility. The majority of the personal risks incorporates a person’s genetic information getting out and being used against them. This can occur due to privacy regulations that are not stringent enough, hacking, and also new laws being passed that requires a person’s genetic information be shared for employment or health insurance.

Ulrich Beck describes our society as living in a modern age where we, as humans, are making ‘new risks’ or ‘man-made disasters’ (Sørensen, 2018). A ‘new risk’ has the potential to be catastrophic to our society because they are not isolated to a specific location nor time (Sørensen, 2018). The ‘new risks’ are thus very hard to predict, and also cannot be insured against because their consequences are unclear and have the potential of being “global, frequently irreparable” (Sørensen, 2018). Examples of these ‘new risk’ include nuclear power plants, pesticides, and as this paper will discuss, DTC-GT services.

There are three overall criteria that DTC-GT services met that makes them a ‘new risk’ and thus leads to people taking personal risks when they partake in the services. One of the criteria is that the new risks cannot be insured against. Insurance companies have come out saying that DTC-GT services have the potential to make them go out of business because insurance is based on a system where everyone pays but only a few eventually require the service. (Schultz, 2013). However, if people have the knowledge that they have a higher risk of acquiring Alzheimer’s or Parkinson’s, then they will take out the extra health insurance that is needed for those diseases and the health insurance companies would be required to pay for those treatments. On the other hand, if a person partakes in DTC-GT services and finds out they have a low chance for many diseases, then they will not take out the extra health insurance and therefore the insurance company will not have that money to offset the cost of the other people, the people who have the disease and require more money from the insurance companies. Insurance companies have therefore stated that they do not want to lose the ability to “utilize all information”, which means that they want to be able use the information from DTC-GT services to determine cost of health insurance on a per person basis (Schultz, 2013). Consequently, there is the personal risk of a person’s genetic information, from DTC-GT services, being given to health insurance companies in the future and be used for pricing. Consequences such as the health insurance companies getting access on a person’s genetic information is what makes the DTC-GT services a ‘new risk’ because they are unknown and cannot be calculated. Additionally, these risks could potentially span multiple generations by affecting the way societies run. It has the potential to lead to insurance companies requiring genetic analyses or using a parents’ genetic information against a child.

A second criteria that DTC-GT services meet is that they are an example of symbolic detoxification. Symbolic detoxification is when the risks from a certain technology, such as DTC-GT, are mitigated through repetition of scientific evidence and reassurance of future control (Mythen, 2004). This symbolic detoxification, however, can be detrimental because it can make the public believe that they have a false sense of security (Mythen, 2004). One way that this false sense of security can occur is through institutional concealment of hazards and also the unchecked development of upcoming risks (Mythen, 2004).

23andMe and Ancestry.com are both institutions that promote the benefit of getting the genetic data because it puts a person in control of their life by understanding their disease risks. In advertisements that have been put out by 23andMe, consumers who have gone through their services describe their experience with words such as empowering, hope, improved quality of life, peace, preparedness, could not wait (*23andMe Story*, 2016; *An Unexpected Discovery*, 2018.; *Empowering Herself*, 2018). These words are used in order to conceal the hazards and convince the public that this is a beneficial service to pay for. Additionally, services such as 23andMe have advertised counselling in order for consumers to understand the data and the validity of the results. However, in Kristen's , a consumer of 23andMe, video she received a packet of information and then had to proceed to her own doctor for more information (*An Unexpected Discovery*, 2018). Furthermore, in a study done by the US Government Accountability Office (GAO) of 15 companies, it was found that this counselling is often lacking (Udesky, 2010). In many cases, the counselling "provided little guidance" and also sometimes it appeared as if they were simply reading off of the report (Udesky, 2010). The limited counseling did not help the consumers to understand what the results actually meant and made them feel as if the results were accurate. One of the reasons for the lack of counselling is because companies

do not want the consumers to understand that there are limitations to the tests because this would lead to consumers not being reassured by the reputation of scientific evidence. One of the main limitations of these DTC-GT tests is that they all use different indicators or SNPs to identify a person's disease risk. Therefore, they do not give a holistic look at a person's disease risk. Additionally, a person's disease risk will change based on what service a person uses (Udesky, 2010).

In addition to the lack of counseling, services such as 23andMe and Ancestry.com also try to reassure against the loss of privacy. Privacy is a concern for many consumers because many DTC-GT services gain a significant amount of revenue by selling their consumers genetic information to pharmaceutical companies for future research (Brown, 2017a). In order for the companies to share a person's data, a consumer must give consent (Brown, 2017a). In the consent, it is stated that a person's data is anonymized (Brown, 2017a). However, what many consumers do not know is the extent of anonymization. In one case, a scientist was able to determine a person's last name by using his Y chromosome and access to a genealogy database (Brown, 2017a). Additionally, there have been concerns regarding hacking. With all of the data being kept on computers and also shared between the companies, there is the chance that hackers will acquire a person's genetic information and name. In 2017, RootsWeb which is associated with Ancestry.com was hacked (Leavenworth, 2018). This led to 55,000 customers being compromised (Leavenworth, 2018).

A third criteria that DTC-GT services meet is that they are an example of organized irresponsibility. Organized irresponsibility is when an institution or government has to recognize that something they are doing, such as providing DTC-GT services, has risks, while also "refuting and deflecting public concerns" (Mythen, 2004). The government has done this with

DTC-GT services by the FDA getting involved in regards to 23andMe and also with policies that have been put in place to limit the personal risks of DTC-GT services.

In 2013, the FDA sent a letter to 23andMe informing them that they had to stop providing their personalized genome service which provided the percent risks of certain diseases (Yim & Chung, 2014). This letter was in response to the lack of 23andMe communication with the FDA (Yim & Chung, 2014). The FDA had been in communication with 23andMe since 2009 in regards to the validity of their results (Yim & Chung, 2014). This was three years after 23andMe's creation but the FDA communication was only revealed to the public in 2013 with the FDA letter. By providing the letter, they were illustrating that the service does have risks and that they needed to evaluate it in order to ensure the validity of it. However, they also had to work to deflect the concerns of people who had already taken the tests. They, therefore, created a carefully stated letter that the analytical validity of the genotype was not a problem per se but just need to be validated and that 23andMe needed to go through the right channels (Yim & Chung, 2014).

The United States government has also illustrated organized irresponsibility by enacting the Genetic Information Nondiscrimination Act (GINA). GINA is a law that makes it illegal for employers to fire someone based on his or her genes and also makes it illegal for health insurance companies to deny coverage or raise rates based on a person's genetic information (Schultz, 2013). This law enabled many consumers to see the potential personal risk that they are taking when performing DTC-GT services but was also trying to show to the public that the government is trying to minimize the personal risks. However, what many consumers are not aware of is that there are many loopholes to this policy. The loopholes are that GINA does not cover life insurance, long-term care insurance, or disability insurance (Su, 2013). This might not

seem like a big deal to many consumers. However, in a study done with patients who got tested for genes associated with Alzheimer's, it was determined that people who have the genes are five times more likely to buy long-term-care insurance (Schultz, 2013). Additionally, there have already been bills in place to try to limit the GINA act even further. HR1212 was a new bill that allowed employers to legally request employees to undergo genetic testing. If the employee refused, then they would have to pay a hefty fine. Additionally, it allowed employers to have access to that data and also other health information (Brown, 2017b). This bill was never enacted but it does show that there are personal risks of the genetic information being used for employment and health insurance in the future.

Discussion of the Personal Risks of DTC-GT Services:

When a person partakes in DTC-GT services, they partake in personal risks that they are not aware of. These personal risks incorporate the uncertainty of the future and also the way our government is set up. As Ulrich Beck once stated "given that social institutions are reliant on public consent, it is in the short-term interests of government, law, and science to conceal and deflect hazards" (Mythen, 2004). Due to the governmental set up, much of our society is built around limiting the awareness of 'new risks' and also institutions being unable to admit potential risks because it would lead to a crisis in legitimacy (Mythen, 2004). If 23andMe or Ancestry.com listed all of the large potential risks such as a person's genomic data being used in the future for employment or insurance, then no consumer would trust them or use their service. Therefore, reflection must be done in order to assess the personal risks that a person takes when performing any service that could be a 'new risk' in today's modern society. The personal risks that are associated with DTC-GT services include a person's genomic data being identified and utilized for employment and health insurance. Additionally, there is a personal risk of misunderstanding the information and being driven to change a person's lifestyle because of it. The main reason

that the misunderstanding is possible is because of the limited counselling that many of the service provide (Kutz, 2010). Many consumers when they sign up for a DTC-GT service do not fully understand the limitations that exist with the service, such as they only test for a small subset of SNPs (Yim & Chung, 2014). Therefore, information in regards to DTC-GT services, how they operate, their limitations, and their risks need to be made easily available in order for consumers to make an informed decision in regards to participating in the service or not.

A limitation of this study was that informational interviews were not able to be conducted. The interviews would have provided great insight into personal experiences partaking in the DTC-GT services. It would allow for information to be gained in regards what a person knew before partaking in the service, and why a person was happy or disappointed by the service. Another limitation was that this research focused solely on the negative sides of the DTC-GT services and not at the positive to determine if the positive outweighed the negatives. A third limitation of this study was that it was not able to provide an analysis on how DTC-GT services differ. A fourth limitation of this study was that it focused heavily on the disease risk services of DTC-GT and not on the other services such as food intolerances, drug response, or paternity.

If this study was to be conducted with more time, interviews would be conducted with people of different age groups and ethnicities who had partaken in a wide range of different services with different companies. Information would then be gathered on their personal experiences, the information they knew before and after partaking in the service, the counselling they received, their emotions in regard to the results, and if any lifestyle changes occurred in response to the results. Additionally, the participants would be asked about how they felt regarding the privacy and if they felt any personal risks regarding conducting the services and if so what.

Conclusion of the Personal Risks of DTC-GT Services:

DTC-GT, such as 23andMe and Ancestry.com, can be categorized as a ‘new risks’ and has many inherent personal risks that are associated with it. The personal risks include the genomic data being acquired for the use of employment or health insurance. If the genomic data was used for health insurance or employment, as some bills have tried to allow, then it would change the way our system is structured. Another personal risk is that a consumer might misinterpret the results which could led to lifestyle changes that are not needed. This is due to consumers not always understanding the limitation of the tests and there not being proper counselling to help inform them of the validity of the results. Therefore, the personal risks associated with DTC-GT services can have a large impact on a person’s life and also future generations. Therefore, this analysis of the personal risks is important to help consumers make conscience decisions in regards to partaking in the services.

References

- 23andMe Story: Two of a Kind, Erika and Kristin*. (2016). Retrieved October 30, 2019, from <https://www.youtube.com/watch?v=IVug8r-hl5o>
- An Unexpected Discovery: Kristin's 23andMe Story*. (2018). Retrieved October 30, 2019, from <https://www.youtube.com/watch?v=Mglolpbkozk>
- Annas, G. J., & Elias, S. (2014). 23andMe and the FDA. *New England Journal of Medicine*, 370(11), 985–988. <https://doi.org/10.1056/NEJMp1316367>
- Badalato, L., Kalokairinou, L., & Borry, P. (2017). Third party interpretation of raw genetic data: An ethical exploration. *European Journal of Human Genetics*, 25(11), 1189–1194. <https://doi.org/10.1038/ejhg.2017.126>
- Bloss, C. S., Ornowski, L., Silver, E., Cargill, M., Vanier, V., Schork, N. J., & Topol, E. J. (2010). Consumer perceptions of direct-to-consumer personalized genomic risk assessments. *Genetics in Medicine*, 12(9), 556–566. <https://doi.org/10.1097/GIM.0b013e3181eb51c6>
- Brown, K.V. (2017a, April 14). *23andMe Is Selling Your Data, But Not How You Think*. Gizmodo. Retrieved February 19, 2020, from <https://gizmodo.com/23andme-is-selling-your-data-but-not-how-you-think-1794340474>
- Brown, K.V. (2017b, March 16). *Why We Should All Be Worried About Congress Eroding Protections Against Genetic Discrimination*. Gizmodo. Retrieved February 19, 2020, from <https://gizmodo.com/why-we-should-all-be-worried-about-congress-eroding-pro-1793271532>

- Caulfield, T., & McGuire, A. L. (2012). Direct-to-Consumer Genetic Testing: Perceptions, Problems, and Policy Responses. *Annual Review of Medicine*, 63(1), 23–33.
<https://doi.org/10.1146/annurev-med-062110-123753>
- CCMG Ethics and Public Policy Committee, Nelson, T., Armstrong, L., Richer, J., Evans, J., Lauzon, J., McGillivray, B., Bruyere, H., & Dougan, S. (2012). CCMG statement on direct-to-consumer genetic testing*. *Clinical Genetics*, 81(1), 1–3.
<https://doi.org/10.1111/j.1399-0004.2011.01789.x>
- Elliott, A. (2002). Beck’s Sociology of Risk: A Critical Assessment. *Sociology*, 36(2), 293–315.
<https://doi.org/10.1177/0038038502036002004>
- Empowering Herself: Sarah’s 23andMe Story*. (2018). Retrieved October 24, 2019, from
<https://www.youtube.com/watch?v=XTbw9n23Ctg>
- Jones, M. (2004). Anxiety and containment in the risk society: Theorising young people and drug prevention policy. *International Journal of Drug Policy*, 15(5), 367–376.
<https://doi.org/10.1016/j.drugpo.2004.08.001>
- Kutz, Gregory. (2010). Direct-To-Consumer Genetic Testing: Misleading Test Results Are Further Complicated by Deceptive Marketing and Other Questionable Practices. United States Government Accountability Office.
- Leavenworth, S. (2018, May 29). *Ancestry wants your spit, your DNA and your trust. Should you give them all three?* McClatchydc. Retrieved February 19, 2020, from
<https://www.mcclatchydc.com/news/nation-world/article210692689.html>
- Markets, R. and. (2019, May 28). *Global \$6.3 Bn Direct-to-Consumer Genetic Testing (DTC-GT) Market to 2028*. GlobeNewswire News Room.

- <http://www.globenewswire.com/news-release/2019/05/28/1851338/0/en/Global-6-3-Bn-Direct-to-Consumer-Genetic-Testing-DTC-GT-Market-to-2028.html>
- Mythen, G. (2004). *Ulrich Beck: A critical introduction to the risk society* /. Pluto Press,.
- Oliveri, S., Howard, H. C., Renzi, C., Hansson, M. G., & Pravettoni, G. (2016). Anxiety delivered direct-to-consumer: Are we asking the right questions about the impacts of DTC genetic testing? *Journal of Medical Genetics*, 53(12), 798–799.
<https://doi.org/10.1136/jmedgenet-2016-104184>
- Roberts, J. S., & Ostergren, J. (2013). Direct-to-Consumer Genetic Testing and Personal Genomics Services: A Review of Recent Empirical Studies. *Current Genetic Medicine Reports*, 1(3), 182–200.
- Sboner, A., Mu, X. J., Greenbaum, D., Auerbach, R. K., & Gerstein, M. B. (2011). The real cost of sequencing: Higher than you think! *Genome Biology*, 12(8), 125.
<https://doi.org/10.1186/gb-2011-12-8-125>
- Schultz, D. (2013, January 17). *It's Legal For Some Insurers To Discriminate Based On Genes*. NPR.Org. Retrieved February 19, 2020, from <https://www.npr.org/sections/health-shots/2013/01/17/169634045/some-types-of-insurance-can-discriminate-based-on-genes>
- Sørensen, M. P. (2018). Ulrich Beck: Exploring and contesting risk. *Journal of Risk Research*, 21(1), 6–16. <https://doi.org/10.1080/13669877.2017.1359204>
- Su, P. (2013). Direct-to-Consumer Genetic Testing: A Comprehensive View. *The Yale Journal of Biology and Medicine*, 86(3), 359–365.
- Udesky, L. (2010). The ethics of direct-to-consumer genetic testing. *Lancet (London, England)*, 376(9750), 1377–1378. [https://doi.org/10.1016/s0140-6736\(10\)61939-3](https://doi.org/10.1016/s0140-6736(10)61939-3)

U.S. Direct-to-Consumer Genetic Testing Market to Hit \$890 Million by 2025: Global Market Insights, Inc. (2019). Retrieved January 30, 2020, from

<https://www.newswire.com/news/u-s-direct-to-consumer-genetic-testing-market-to-hit-890-million-by-21008222>

Williamson, R., & Duncan, R. (2002). DNA testing for all. *Nature*, 418(6898), 585–586.
<https://doi.org/10.1038/418585a>

Yim, S.-H., & Chung, Y.-J. (2014). Reflections on the US FDA’s Warning on Direct-to-Consumer Genetic Testing. *Genomics & Informatics*, 12(4), 151–155.
<https://doi.org/10.5808/GI.2014.12.4.151>

Zettler, P. J., Sherkow, J. S., & Greely, H. T. (2014). 23andMe, the Food and Drug Administration, and the Future of Genetic Testing. *JAMA Internal Medicine*, 174(4), 493–494. <https://doi.org/10.1001/jamainternmed.2013.14706>