

Privacy and Me: How Genetic Testing Threatens our Privacy and Aids

Discriminatory Practices

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## Privacy and Me: How Genetic Testing Threatens our Privacy and Aids Discriminatory Practices

Genetic Testing has quickly become a large topic of discussion in our society with companies like 23andMe being promoted avidly through social media and media outlets like BuzzFeed. The tests promise to reveal information that can reconnect us with our roots (Roche & Annas, 2006) and inform us about potential genetic predispositions to certain diseases (Eng, Hampel, & Chappelle, 2001). However, Americans should be cautious before shipping off their DNA to their chosen genetic testing company. Due to an influx of government and corporate intervention, the use of DNA testing kits could come back to limit our access to health insurance and lead to a violation of our rights (Baudhuin, 2014) and privacy (Rodriguez, 2018) and we, as a society, should be actively protesting against these practices.

This research paper aims to inform the public on how entities like health insurance companies and law enforcement have successfully begun using DNA testing results from consumer genetic testing kits in their daily operations. Using the moral framework of utilitarianism, law enforcement suggests that by using these databases they can make the world a safer place even if it violates the privacy of consumers. Instead of having the right to consent or refuse law enforcement's requests for DNA, they can now simply use consumer DNA testing results without ever getting courts or lawyers involved (Leavenworth, 2018).

In addition, many insurance companies want access to the results of any genetic testing a potential client may have completed before granting

coverage. Currently, they cannot force consumers to take a DNA test, but they can use existing DNA test results to deny coverage or to raise a consumer's premium if they believe the results present them as a higher risk. If someone has a family history of heart disease, for example, this could make health insurance harder to obtain or afford despite it being the leading cause of death in the United States and worldwide.

It's important to note how loosely regulated genetic testing companies are by our current laws. Though these companies claim to have consumer-friendly privacy policies (many of which claim to never sell DNA or allow law enforcement to use their databases without a warrant), there is nothing stopping them from altering these policies at a later date. The most notable example is a recent case where FamilyTreeDNA gave the FBI complete access to their database without informing their customers (Haag, 2019).

Lastly, we must ask if it is ethical for these consumer testing companies to enter other countries to take their DNA for database building missions. Without this process, these companies couldn't provide their advertised service of finding a consumer's ancestry. In reality, their entire service is built on the exploitation of less fortunate people for the entertainment of Americans.

### **Statement of Ethics**

When looking into discussions and research on genetic testing, I recognized that I had history with the topic which may have helped form my opinion on the issue. Like many, I've always wanted to know more about my

ancestry and consumer genetic testing kits are modeled to fulfill those desires. After being persuaded by BuzzFeed videos and glowing reviews on social media, I decided to make an impulse buy. During Amazon Prime Day last year, I ordered two consumer genetic testing kits for around \$150. I was extremely excited up until the very moment that I received the package. Something had changed and I suddenly felt apprehensive about sending off a tube of spit to two companies that I didn't know much about. Something told me to do more research into these companies before opening each kit and sending in my DNA. After looking into each company, I found that they had both made headlines recently for their relationship with law enforcement and privacy policies that allowed them to give and sell DNA as they pleased. This made me seriously uncomfortable. I was minutes away from opening each kit and adding myself into what has become an essential DNA database for law enforcement and large corporations. I wanted to know more about my ancestry, but not enough to place myself into a government system. After this discovery, I packed up the kits and returned them to Amazon the next day.

I personally believe that what genetic testing companies are doing with their customer's DNA is immoral and a violation of our privacy based on both my own personal experience and the research that I have done throughout the semester. I'm going into media and journalism as a profession and thus find myself wanting to inform the public of injustices they may be unaware of. I feel that if consumers of these kits were aware of what was being done with their DNA, they would be less likely to purchase them. There is no mention of these

companies' relationship with law enforcement or biotech companies when purchasing the product. There is also no clear indication of future changes in the privacy policies that claim to protect user DNA once it's submitted. These unethical moves lead to outrage and feelings of betrayal amongst consumers after these companies decide to later trade their privacy for money or political gain.

### **Brief History of Genetic Testing**

In 1988, Colin Pitchfork became the first person convicted of murder through the use of DNA fingerprinting (Cobain, 2016). The murder and rape of Dawn Ashworth set the precedent that allows for DNA to be admissible in court. This case ensured that genetic testing would soon become integrated into law enforcement and would later spread throughout the rest of our government's infrastructure.

### **Current Ethical Issues**

#### **Law Enforcement**

Since DNA evidence was first introduced into the courtroom, our criminal justice system became dependent on it to close cases and prove guilt to juries. When a jury hears that there is DNA evidence against a suspect, they are already predetermined to be guilty. However, this isn't necessarily true. Crime labs only test against a small number of genetic markers compared to genetic testing companies. In 2015, police used AncestryDNA to investigate a man who

matched 34 of 35 genetic markers of their suspected killer (Brown, 2018). He and his son were eventually ruled out, but if they tested against a smaller number of genetic markers like many crime labs, the innocent man may have been a match. The general public is not aware of these facts which could lead to the incarceration of someone who may truly be innocent. This is one reason why we should worry when we hear that law enforcement has begun acquiring access to genetic databases from consumer DNA testing companies.

In the case of FamilyTreeDNA, where the company willingly gave the FBI access to its database, 60% of Americans of European descent can be identified through just their database even if they did not submit their own DNA due to extended family (Haag, 2019). The number is soon expected to jump to 90%. The method of using a distant relative's DNA from genetic testing companies to find the true suspect became popular after law enforcement used it to catch the notorious Golden State Killer in 2018 (Brown, 2018).

However, this method targets predominantly white Americans since they are the primary users of DNA testing services in the United States. In order to mediate this obstacle, law enforcement has turned to targeting young minorities with a new tactic to obtain their DNA. Children are being randomly stopped by police and forced to hand over their DNA through swabbing without being informed that they have the right to refuse (Leavenworth, 2018). Law enforcement is actively trying to build their databases by taking advantage of the children they're supposed to be protecting. The "if you have nothing to hide" argument should not be an adequate excuse because it ignores the fact

that law enforcement has been using immoral and deceptive practices to obtain DNA and inadvertently putting minors into our criminal justice system.

Law enforcement's desperation for DNA evidence has led to an extreme violation of our privacy rights and, in some cases, a lack of a fair trial. Hiding behind the guise of utilitarianism, innocent children and consumers of DNA tests are now in the same system as actual felons. However, instead of breaking the law, they were simply victims of unregulated privacy policies and unlawful search and seizure for their DNA.

### **Insurance**

GINA was passed in 2008 and aimed to protect the public against a type of discrimination that wasn't covered under preexisting laws. Under GINA, employers and health insurance companies could not request genetic test results or discriminate based upon them (Zhang, 2017). However, the law, which was hailed as the "first major civil-rights bill of the century", has some major loopholes in that it doesn't cover education, housing, and even other types of insurance like life insurance and disability insurance. This is important because it shows how insurers today have gotten to the point where they are now legally able to deny coverage based on genetically discriminatory practices.

I believe that it is unethical to deny someone life insurance because they might have some risk of a genetic disease passed down from a distant relative, but the practice is not uncommon. In 2015, a 36-year-old woman was denied life insurance because her genetic test results indicated that she was positive for the BRCA 1 gene associated with increased risk of breast and ovarian cancer

(Farr, 2016). However, not everyone with the BRCA mutation develops cancer and preventative treatments reduce the likelihood that they'll ever get sick. This did not stop insurers from denying her coverage and showcases how certain entities are allowed to legally discriminate against people using genetic testing.

### **Counterargument**

Some argue that our current laws are sufficient when dealing with the issues surrounding genetic testing. One duo, Wauters and Van Hoyweghen, say that genetic discrimination isn't as rampant as the general public believes (2016). The two state that there is little evidence of the occurrence of genetic discrimination and that there are laws that prevent it from happening. Still, people are concerned about the possibility of genetic discrimination to the point where they let fear influence their health and important life decisions.

I would argue that laws like GINA are insufficient in protecting consumers because they have loopholes that have already been exploited and they have not kept up with advancing technologies. As previously stated, these laws do nothing to stop genetic testing companies from changing their privacy policies (Haag, 2019), sharing consumer DNA (Brown, 2018), and preventing genetic discrimination from insurers (Zhang, 2017). Therefore, I would conclude that the public's fears are valid. If these laws cannot successfully protect our privacy and prevent genetic discrimination today, how can we expect them to govern our society in the future?



### **Future of Genetic Testing: Designer Babies**

Designer babies raise new issues in genetic testing that bring about a new type of discrimination. Designer babies are beings created to be, objectively, better than the rest of humanity. In Young Rojahn's article, she discusses the implications that come with creating designer babies after 23andMe was granted a patent in 2013 for a method that would allow parents to predict their child's traits based on their DNA (2013). Designer babies are described as embryos that have been modified to have desirable traits and 23andMe said the tool could potentially be used in fertility clinics to do so. Bioethicists questioned the morality of the company's patent in an editorial article and called for 23andMe to abstain from offering any products based on the patent and to instead use it to prevent others from creating designer baby systems. However, 23andMe said their system can only predict the likelihood of traits and improve the odds of certain traits. Scientists do not yet know the genetic basis for things like intelligence and creativity. 23andMe said that it only intends to use the patent for matching customers together to see the odds of things like their offspring's eye color or lactose tolerance.

For students in the School of Informatics, Computing, and Engineering, the topic of designer babies may span back to I101 where we are introduced to *Gattaca*. The film depicted genetic discrimination in a world where naturally conceived humans lived beneath genetically modified humans in society and this status determined everything from their treatment in society to what kind of job they could have. While we're not there yet, this type of discrimination is

immediately what my mind goes to when designer babies are brought up. I'm against the idea of creating people who are "flawless". When this technology is available, there's no doubt that it will be expensive and limited only to the upper class. Their artificially boosted performance will only further the divide between the rich and the poor and encourage more discrimination in society. Designer babies may also lower our gene diversity to the point where we're no longer unique and end up losing the right to call ourselves individuals.

### **Conclusion**

When it comes to genetic testing being used for questionable and immoral means, the public and government entities have the power to enforce change. Government agencies like the Food and Drug Administration (FDA) have the power to govern and limit the reach of consumer genetic testing companies and have exerted it in the past when limiting 23andMe's integration of health care features (Robbins, 2018). However, there's a conflict of interest in play when asking the government to pass legislation on genetic testing companies because of law enforcement's use of their databases and insurance companies lobbying for the same access. When it comes down to it, we as a society need to start actively campaigning to enforce change so that we can protect our rights and privacy. Too often, we allow ourselves to become docile to large corporations like when FamilyTreeDNA revealed that they've been giving the FBI complete access to their customers' DNA. As usual, there was initial outrage on social media, but people eventually seemed to forget about it.

FamilyTreeDNA is still violating the trust of consumers by sharing their DNA with law enforcement and we've let them get away with it by being quiet. When we see injustices like these from large companies, we need to hold them accountable by making sure that our voices are continuously heard for more than just a day. This is how we can enforce real change against the misuse of our most sensitive data.

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## References

- Baudhuin, L. M. (2014). The FDA and 23andMe: violating the First Amendment or protecting the rights of consumers? *Clinical Chemistry*, 60(6), 835–837.  
<https://doi.org/10.1373/clinchem.2014.223321>
- Brown, K. V. (2018, April 27). What the Golden State Killer Case Reveals About Your Genetic Privacy. *Gizmodo*. Retrieved from  
<https://gizmodo.com/what-the-golden-state-killer-case-reveals-about-your-ge-1825597821>
- Cobain, I. (2016, June 07). Killer breakthrough – the day DNA evidence first nailed a murderer. *The Guardian*. Retrieved from  
<https://www.theguardian.com/uk-news/2016/jun/07/killer-dna-evidence-genetic-profiling-criminal-investigation>
- Eng, C., Hampel, H., & Chapelle, A. de la. (2001). Genetic Testing for Cancer Predisposition. *Annual Review of Medicine*, 52(1), 371–400.  
<https://doi.org/10.1146/annurev.med.52.1.371>
- Farr, C. (2016, April 06). If You Want Life Insurance, Think Twice Before Getting A Genetic Test. *Fast Company*. Retrieved from  
<https://www.fastcompany.com/3055710/if-you-want-life-insurance-think-twice-before-getting-genetic-testing>
- Haag, M. (2019, February 04). FamilyTreeDNA Admits to Sharing Genetic Data with F.B.I. *The New York Times*. Retrieved from  
<https://www.nytimes.com/2019/02/04/business/family-tree-dna-fbi.html>

- Leavenworth, S. (2018, October 05). If police try to take DNA from your kid, do they need your consent first? *McClatchyDC*. Retrieved from <https://www.mcclatchydc.com/news/crime/article219443025.html>
- Robbins, R. (2018, October 31). 23andMe test cleared to help patients determine how well drugs may work for them. *STAT*. Retrieved from <https://www.statnews.com/2018/10/31/fda-clears-23-and-me-genetics-test-drug-effectiveness/>
- Roche, P. A., & Annas, G. J. (2006). DNA Testing, Banking, and Genetic Privacy. *New England Journal of Medicine*, 355(6), 545–546. <https://doi.org/10.1056/NEJMp068136>
- Rodriguez, M. (2018, September 10). You Discovered Your Genetic History. Is It Worth the Privacy Risk? *Fortune*. Retrieved from <http://fortune.com/2018/09/10/genetic-history-test-privacy-risk/>
- Wauters, A., & Van Hoyweghen, I. (2016). Global trends on fears and concerns of genetic discrimination: a systematic literature review. *Journal of Human Genetics*, 61(4), 275–282. <https://doi.org/10.1038/jhg.2015.151>
- Young Rojahn, S. (2013, October 03). Should You Worry about 23andMe Patenting "Designer Babies"? *MIT Technology Review*. Retrieved from <https://www.technologyreview.com/s/519856/should-you-worry-about-23andme-patenting-designer-babies>
- Zhang, S. (2017, March 13). The Loopholes in the Law Prohibiting Genetic Discrimination. *The Atlantic*. Retrieved from

<https://www.theatlantic.com/health/archive/2017/03/genetic-discrimination-law-gina/519216/>