Exploring the Risks of Genetic Testing: A Look at Privacy Concerns

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1 Introduction

Nowadays, there is no limitation on access to genetic testing in the United States. Genetic tests have become increasingly popular due to their being inexpensive. In recent years, many direct-to-consumer (DTC) testing has become exponentially cheaper and more accessible than ever, now only costing about $99 [Grandhi and Plotnick(2022)]. Individuals are able to send a sample of their saliva and in turn learn about their family history and possible health concerns. The growing use of DTC tests has also caused a rise in privacy concerns with websites like, like *23andMe* and *Ancestry.com*. From these websites, people are able to download their DNA and send it to third-party sources to learn even more about themselves. Both people who have and have not taken a genetic test encounter possible fears and concerns of the possible malicious uses of these tests. Along with this, genetic testing may be used on larger scales in order to benefit a country or hurt other countries.

2 Background

DTC genetic tests allow people to share their DNA results on a platform to find relatives who have also given their DNA samples to the same service [King(2019)]. They may also provide a background on genetic mutations, and possible inherited diseases, as well as provide information about ethnic or heritage background. These DTC services are beginning to allow users to download their own genetic data [Ney et al.(2020)]. A genetic data file can be downloaded from these websites. Once downloaded, this file may be sent to any third-party company in order to be analyzed further for users to gain even more knowledge about themselves. This also leads to more questionable safety and privacy issues that may affect individuals on a smaller scale as well as countries as a whole. .

3 Malicious uses of genetic information

An individual's genetic information can show everything about them. As of now, DNA is unable to be changed. This means a person's specific traits, diseases, ethnic background, relatives, and so much more can be figured out through a small sample. In China, this information is being exploited as a way to control society. China has been using DNA and facial recognition to identify people that are a part of the Muslim Uighur population and put them in detention camps [King(2019)]. This brings up more concerns regarding how other countries could possibly abuse this power now and in the future.

Genetic warfare is another concern with the uprise of genetic testing. Research has been continuously worked on for possible genetic weapons, but never been perfected [Biberman(2021)]. It would be very difficult to control what specific people would be affected by the virus. Unlike nuclear weapons, genetic weapons would be difficult to see being developed as they may look like normal research facilities. This would make it difficult for countries to tell if others are secretly in the process of creating something that could be very deadly. Along with this, there are not many regulations around genetic warfare.

On an individual level, studies have been done to compare people's privacy concerns with genetic testing. In this study, participants who have already received genetic test results and those who have not were asked questions about their concerns. Their answers were then compared [Grandhi and Plotnick(2022)]. It was found that those who have received a DNA test have fewer concerns with privacy. Participants were also asked their reasoning for their concerns. These are split into unauthorized and unethical misuse concerns.

The unauthorized misuse concerns include situations where participants are unaware of the company's terms of service or changes, as well as privacy concerns. One common fear was the terms of service being changed unknowingly after the company has already taken data. If not watched carefully, this could cause a participant to have their data shared without knowing or without their original consent. Another worry was if a company is too private with their data, it would be hard or even impossible for some people to find their biological families.

Unethical misuse concerns include situations where it would not be morally correct for a company to use or give out information. One of these concerns was allowing insurance companies to use genetic information to look for medical conditions that can then be deemed as

preexisting and allow them to charge more money than they would if they did not have the information. Other concerns include discrimination from employment, healthcare, medicare, social security, as well as the government. Similar to the example given about China before, people are also nervous about a biological tracking weapon being created by governments.

4 Beneficial uses of genetic information

There are not only negatives to genetic testing, but there is also a lot of potential for positive effects. Now, for many individuals, getting DNA results can be very useful. This is most important for those who want to find out about genetic health information [King(2019)]. People may not know who their biological family is or may not be able to contact them. For these people, being able to find out possible hereditary diseases or inherited conditions they may have can be very useful to help prevent and prepare for possible concerns later in their lives. These people that do not know their biological family may also be able to find relatives through sites like *23andMe* or *Ancestory.com*. If relatives have also submitted their DNA results, these sites will put together a family tree that can date back generations.

On a larger scale, the genetic information these sites store can also be useful for law enforcement. Given a DNA sample, 60% of people would be able to be found through a DNA database that contains 1.28 million DNA samples from different individuals [Ney et al.(2020)]. Along with this, a database with a very small percentage of the population would be able to discover a third cousin for most people. One of the most well-known examples of this is the Golden State Killer case. By obtaining a sample of his DNA, the police were able to use a third-party genetic genealogy service, called GEDmatch, to find one of his cousins. GEDmatch takes an individual's genetic data file and matches it with others who have also submitted their files to the database. These files can be downloaded from sites such as *23andMe* and *Ancestory.com*. With the proper DNA samples and databases, the police have the potential to find many criminals by simply using relative matching on these sites.

5 Conclusion

While DTC genetic testing can provide valuable insights into an individual's family history and potential health risks, it also carries unknown risks and negatives. China's use of genetic information and its development of facial recognition as well as individuals' concerns

with unauthorized and unethical uses of genetic information is only the beginning of what could be a deadly weapon in the future. These concerns highlight the importance of considering the privacy risks and potential consequences of participating in genetic testing, as well as the need for regulations to protect against the malicious use of genetic information. This is why it is important to carefully consider the potential pros and cons before undergoing genetic testing.

References

[Biberman(2021)] Yelena Biberman. 2021. The Technologies and International Politics of Genetic Warfare. *Strategic Studies Quarterly* 15, 3 (2021), 6–33.

[Grandhi and Plotnick(2022)] Sukeshini A Grandhi and Linda Plotnick. 2022. Do I Spit or Do I Pass? Perceived Privacy and Security Concerns of Direct-to-Consumer Genetic Testing. *Proceedings of the ACM on Human-Computer Interaction* 6, GROUP (2022), 1–26.

[King(2019)] Jennifer King. 2019. " Becoming Part of Something Bigger" Direct to Consumer Genetic Testing, Privacy, and Personal Disclosure. *Proceedings of the ACM on Human-Computer Interaction* 3, CSCW (2019), 1–33.

[Ney et al.(2020)] Peter Ney, Luis Ceze, and Tadayoshi Kohno. 2020. Genotype Extraction and False Relative Attacks: Security Risks to Third-Party Genetic Genealogy Services Beyond Identity Inference.. In *NDSS*.

[Biberman(2021)] [Grandhi and Plotnick(2022)] [King(2019)] [Ney et al.(2020)]