Corporate Sharing of Genetic Data: Data Goldmine or Pandora’s Box?

In recent years, genetic data analysis companies have sold DNA test kits to consumers that report data on their health and ancestry. With a single sample of a customer's saliva, companies like 23andMe provide genetic insights that can help to predict health outcomes. In October 2018, 23andMe sold genetic data to the multinational healthcare company, Glaxo SmithKline, in an effort to develop new pharmaceuticals (Gavin, 2018). Traditional biobanks for genetic data struggle to remain profitable and sustainable, which has driven research institutions towards private genetic data analysts (Spector-Bagdady, 2018).

DNA analysts argue that they—not the clients—are the rightful owners of the collected genetic data. After all, they are the ones who provide the tests that allow clients to learn about their genetics and to contextualize that information in the first place. More than that, there are many different companies that customers can choose from if they wish to opt for more or less privacy for their data. For instance, in their biobanking consent document, 23andMe informs and requires their clients' consent to have their genetic data accessible for the company and its contractors to “access and analyze [their] stored sample[s]” (23andMe). Comparatively, the genealogical testing service, Ancestry, promises to delete clients' genetic information within 30 days. Perhaps most radically, the genetics-testing company, Helix, informs clients that they may “store your DNA indefinitely” even if they are willing to throw away collected saliva samples upon request (Brodwin, 2018). The varying degrees of regard for consumer privacy in the DNA testing market allows consumers to make their own choice with respect to their personal concern for the matter.

Moreover, many individuals who are at risk for or suffer from undesirable medical conditions would benefit from the accessibility of the data from DNA analysis service users. In recent years, many valuable scientific studies have incorporated this data to increase their participant population. As an example, 23andMe currently uses such data to collaborate with research institutions in studies concerning the genetic factors involved in autism (Grove, et. al., 2019), ADHD (Demontis, et. al., 2018), as well as alcohol-use disorders and neuropsychiatric conditions (Sanchez-Roige, 2018). With tens of thousands of individuals' genetic data available, this data enables scientists to address many of our medical concerns and for these customers to be participants in this important research.

https://liberalarts.utexas.edu/ethicsproject/
On the other hand, could genetic data companies be opening a pandora’s box of privacy violations? According to one study, only 23% of survey participants were comfortable with the commercialization of their biospecimens (Spector-Bagdady, 2018). Opting in for the service, for many customers, is quite different from opting in for that data to be sold and used in research studies. When customers sign up for genetic testing, most do not read through the lengthy terms of service agreements that detail the conditions for the services (Niemiec and Carmen Howard, 2016). Hence, many customers are not in a position to opt-in for “informed consent” to various uses of their genetic data or to voice their concerns about the privacy of their data.

Furthermore, the consequences of unbridled access to medical data are also harrowing to imagine. In 2013, 23andMe was found in violation of the law specifically for “selling tests of undemonstrated reliability as predictive tests for medical risk factors” (Mamzer-Bruneel, 2016). If the technology still fails to demonstrate its reliability, we should be wary of interpretations drawn from that data. In particular, should that data be bought and sold by private companies, research institutions, and even the government, we should be cautious about whether it is being used in our interest. For instance, if genetic data were to be released to the state, narrow and unconsciously biased interpretations of it could lead to discrimination in the interest of reducing public expenditures for those with undesirable DNA. For instances, clients may lose health benefits if employers learn that they are at risk for certain medical diseases. In this way, clients of genetics companies may have more to lose than just their data for signing up for these testing and analysis services.

The choice to opt for genetic testing in itself is a challenging decision. One can learn that one may be predisposed for many undesirable medical outcomes, which can be difficult to contend on its own. In addition, consumers must also decide how much they are willing to allow very personal data to be available in order to learn more about themselves. Given the possible promises and concerns raised, can we really weigh our desire to learn more about ourselves against our concerns for our privacy? Should we have to?

Discussion Questions:

1. What values are in conflict over selling genetic data? What is worrisome about this practice?

2. Is this primarily a legal or ethical controversy? Explain your reasoning.

3. Do DNA geneticists or clients maintain the rights over the client’s genetic data? Why or why not?

Further Information:

Demontis, D., Walters, R.K., Martin, J. et al., “Discovery of the first genome-wide significant risk loci for attention deficit/hyperactivity disorder.” *Nature Genetics*, November 2018. Available at: https://www.nature.com/articles/s41588-018-0269-7#citeas

“DNA Genetic Testing & Analysis.” *23andMe*. Available at: https://www.23andme.com/about/biobanking/?URL=https://www.23andme.com/about/biobanking/&utm_source=cj&utm_medium=affiliate&utm_campaign=us_evergreen_sales_prs&utm_content=Affiliates&utm_term=Skimlinks&cjevent=d261b770fa6c11e9801502c20a1c0e10


Authors:

Florent Marchais & Alicia Armijo
The Ethics Project
University of Texas at Austin
January 15, 2020

https://liberalarts.utexas.edu/ethicsproject/