OPINION PIECE

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Innovative Commercial and Private Genetic Testing Raises Privacy and Confidentiality Concerns

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ARTICLE INFORMATION

Recieved 13 October 2018
Accepted 11 November 2018

Available online:
26 November 2018

Editors:
Caitlyn Wilcken
Ashwinie Sivakumar

Layout Editor:
Youssef El-Sayes

ABSTRACT

Obtaining information about your genes can be as easy as swabbing your cheek for DNA testing. Companies that offer direct-to-consumer genetic testing with saliva have the authority to collect and share personal data as well as test results from their clients. However, patients want their personal information to be protected and although these companies ask for consent before sharing information with third-party sources, companies have the right to use client data to initiate research or improve their business. Genetic testing companies need to respect their clients and understand that they are paying for a service which deals with sensitive information that individuals may not want collected and stored.

Keywords: DNA testing, privacy, data, companies, genetics, ancestry

INTRODUCTION

Individuals are now turning towards companies such as 23andMe and Ancestry to learn more about their family history and health screening. 23andMe is also known for their direct-to-consumer genetic testing with saliva that can report whether the individual carries genetic indicators associated with health conditions such as celiac disease, late-onset Alzheimer's disease, and Huntington's disease[1]. Many individuals that use these companies are fascinated by their results. However, a majority of individuals are unaware that once they have sent their DNA, it is stored in the company's database. Thus, the company now owns the right to the data.

TERMS AND CONDITIONS

Commercial and private genetic testing companies should not be permitted to collect and share personal data or DNA test results of their clients. The privacy policy of Ancestry states, "Once our laboratory partner has produced your DNA Data, the DNA and saliva (also referred to as "biological samples") are stored so that they can be available for future testing"[2]. Furthermore, 23andMe states in their privacy statement that they "do use and share aggregate information with third parties in order to perform business development, initiate research, send you marketing emails and improve services"[3]. Although these statements are available for everyone to view, a CBC article regarding privacy implications argues that these policies are time-consuming and tedious to read. Therefore, individuals accept the terms

and conditions of the service without changing the default privacy settings[4].

ACCESS TO PERSONAL GENOMIC DATA

A CBC article from 2018 mentions that Canadians are protected by the Genetic Non-Discrimination Act. Therefore, companies are not permitted to share DNA testing or results with insurers or employers[4]. However, Canadians who purchase DNA kits in other countries are not protected by the Canadian Act and they must follow the rules of the country in which the kit is made[4]. Additionally, the National Human Genome Research Institute allows researchers to access genetic and individual research data upon request. Access includes databases of genotypes and phenotypes, the National Database for Autism Research, and The Cancer Genome Atlas[5]. In the United States, these databases are under "controlled access". Nonetheless, some data is readily accessible while keeping the identities anonymous.

A MacLean's article from 2017 states that customers are under no impression that they have consented to the collection and storage of their private information and results[6]. Moreover, at any time, this information can be sold to third parties such as pharmaceutical or insurance companies for targeting individuals with marketing schemes[6]. Another article published by CNN in 2016 makes an appalling disclosure regarding a team of American and Israeli scientists who could reconstruct the identity of individuals who provided anonymous genetic samples simply through readily available databases on the internet[7]. Researchers analyzed data of approximately 1.28 million people and discovered that they can be tracked through open genealogical databases[7]. Through extensive examination, researchers were able to determine the individual's age, place of residence and other factors[7]. An article from CBC also states that if people use their Facebook or Twitter accounts to sign into 23andMe or Ancestry, the companies will collect profile data, age range, friends and followers if their privacy settings are not restricted[4].

CONCLUSION

Genetic testing websites house an individual's most sensitive information that is often shared unknowingly. A majority of users click the "I Agree" option and are unaware of the hidden details in the terms of use. Although it is highly unlikely to ban these websites from using client data without consent, nor storing and sharing it, these companies must be transparent about how exactly they handle sensitive information. The terms and conditions are usually written by lawyers which may not provide transparency to costumers and thus, it should be written with the general audience in mind. Most often, users do not consider changing the default privacy settings or are unaware that they are able to. Companies should take responsibility to ensure that people can select the most private options available. Information collected by these companies is not only risky for the individual obtaining the test, but for their family, relatives, and children.

ACKNOWLEDGEMENTS

I would like to express my sincere gratitude to Dr. Katie Moisse and Learning Support Librarian Abeer Siddiqui for their continuous encouragement, support and guidance in writing this piece.

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