

Title: The Secrets of Your Ancestry: An Examination of the Rise in Popularity of Consumer Genetic Testing and Privacy Concerns

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Direct-to-consumer genetic testing (DTC-GT) companies such as 23andMe and AncestryDNA have revolutionized the health market through easy-access ancestry and health risk reports. By the start of 2019, there were over 26 million consumers in the market (Regalado). As the DTC market continues to expand and grow rapidly, consumers have expressed concern over the lack of privacy laws and the security of their genetic data (Hendricks-Sturup).

The prevalence of DTC-GT companies in the twenty-first century has prompted new policies and regulation. In the United States, the Genetic Information Nondiscrimination Act was passed in 2008 to prevent discrimination by employers and health insurers in the light of the DTC-GT growth (NHGRI). However, this legislation does not fully protect DTC-GT users. Over the years, companies like 23andMe have also faced criticism from federal institutions such as the U.S. Food and Drug Administration (FDA) for failing to provide proof of clinical validity in its health-risk reports (Zettler). FDA oversight over DTC-GT companies has increased in this decade; however, many companies still make their privacy conditions unclear and leave many consumers vulnerable to having their data sold to other companies, especially for medical research use. The FDA leaves gaps in its regulation and does not fully address consumer concerns (Martinez). My research project will examine popular DTC-GT companies and their privacy laws. I will conduct a survey to investigate the reasons for the popularity of DTC-GT companies with respect to their advertising methods, as well as test user understanding of their consumer privacy.

Works Cited

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