

## ***Balancing Innovation and Ethics: The Role of Genetic Testing in Health and Identity***

DOI: 10.52214/vib.v11i.13281

Anisa Patel\*

### ABSTRACT

The growth of direct-to-consumer genetic testing promises insight into health risks and ancestral roots. This essay examines how at-home DNA kits empower users to detect potential genetic conditions early, create personalized health strategies, and gain a deeper understanding of their lineage. However, the essay cautions against overreliance on these tests to define identity, noting that genetic data alone may be incomplete or imprecise. Ethical questions also arise around data privacy, psychological impact, and the need for rigorous scientific validation. By exploring cost concerns and regulatory gaps, this essay underscores the importance of balancing innovation with responsible usage. Ultimately, genetic testing can offer valuable information for proactive healthcare and self-discovery with professional medical consultation and ethical safeguards.

**Keywords:** genetic testing, DNA, identity, health, lineage, ancestry, ethics, privacy, DNA testing

### I. INTRODUCTION

Interest in genetic testing surged as social media and online marketing spread awareness about kits that can help people discover their DNA makeup. Genetic testing is the sequencing of human DNA to find genetic anomalies or mutations and can be used for many purposes, including discovering ancestral lineage. Recent innovations have made DNA testing more accessible, easy, and affordable. Currently, some of the main genetic testing companies include 23andMe and AncestryDNA, where people can effortlessly find out information about their health and family history. While genetic testing kits can improve quality of life by providing insight into health problems and helping people understand their lineage, they should not dictate identity or replace consulting medical experts.

\* Anisa Patel, BS Purdue University

© 2025 Anisa Patel. This is an open access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction, provided the original author and source are credited.

## II. HOW GENETIC TESTING WORKS

Genetic testing kits create an easy process for people to test their DNA in the comfort of their homes. Usually costing from \$59 to \$99, most DNA test kits include a small container for customers to spit in or a swab to collect cells from the inside of their cheeks. Then, the consumer sends the kit to a lab, where scientists isolate their cells and analyze their genes, comparing the gene alleles to those in the company database.<sup>1</sup> According to *MIT Technology Review*, “By the start of 2019, more than 26 million consumers had added their DNA to four leading commercial ancestry and health databases.”<sup>2</sup> The contribution of data from over 26 million people enhances the accuracy of genetic testing, as a larger dataset allows for more precise analysis and insight. After the lab receives the sample, scientists use DNA sequencing, the process of determining the sequence of nucleotides, to map out the genetics of a person. DNA nucleotides, the organic molecules that form DNA, contain four bases: adenine (A), cytosine (C), thymine (T), and guanine (G). These four bases make up the instructions that tell the body which molecules to create, allowing scientists to identify specific health and lineage traits.

## III. HEALTH BENEFITS OF GENETIC TESTING

A key benefit of genetic testing is that it helps people understand and gain early awareness of possible health problems. From DNA testing kits, individuals can learn whether a genetic condition runs in their family before symptoms appear. Mayo Clinic points out, “If you have symptoms of a disease that may be caused by genetic changes, sometimes called mutated genes, genetic testing can reveal if you have the suspected disorder. For example, genetic testing may be used to confirm a diagnosis of cystic fibrosis or Huntington's disease.”<sup>3</sup> Genetic testing can also reveal illnesses that may only be caught on the genetic level. For instance, Huntington's disease, an inherited condition in which nerve cells in the brain break down over time, can only be detected through DNA testing. By using a genetic testing kit, people can learn if they carry inherited illnesses such as Huntington's disease and cystic fibrosis sooner and make adjustments to their lifestyle to improve their health.

A person receiving genetic testing can potentially prevent or treat health issues earlier and save their lives. Genetic testing can help individuals identify whether they carry an increased risk of cancer, Alzheimer's, or other diseases, and find the safest and most effective treatment for them based on their DNA.<sup>4</sup> Advancements in technology, such as genetic testing, have made healthcare more personalized, resulting in greater accuracy and more efficient treatments. More than a third of home testers consult a medical professional and half share their results with others, an important step in understanding and decoding the results from genetic tests.<sup>5</sup>

In enabling individuals to gain insight into their health predispositions, genetic testing encourages behavioral adjustments and the adoption of healthier lifestyle habits. For example, with dieting, many people lose motivation to continue nutritious eating habits and exercise when they do not notice instant results. However, genetic testing can help people stay committed by providing confidence that their efforts align with their genetic profile and will yield results over time. Observing tangible results and adding other incentives will push users to continue improving themselves.

## IV. GENETIC TESTING AND PERSONAL IDENTITY

Although genetic tests can help individuals trace their lineage, the results should not be used to form their identity. Each genetic testing company maintains a genetic database used to decipher ancestral history but sometimes lacks all the data needed to create a fully accurate reading. The *American Journal of Human Genetics* conducted a field study on how people view their identity after taking DNA testing kits. The study

revealed that companies provided underdeveloped results, stating, “pie charts showing percentages of ancestry are grossly oversimplified, revealing a probability rather than a definitive answer. They are based on science that is meant to address questions at the population level, not about specific individuals.”<sup>6</sup> Genetic testing companies predominantly rely on the data that their consumers send, with databases differing for each business. Companies base their results on probability and population-level statistics, grouping people based on similar genetic makeup. For instance, companies possess more data on Caucasians than on Native Americans due to the larger population size of Caucasians and their substantial representation within the consumer base. Even DNA testing company 23andMe states, “Currently 23andMe has several features that can reveal genetic evidence of Indigenous American ancestry, although they are not considered a confirmatory test or proof of such ancestry in a legal context.”<sup>7</sup> These companies cannot fully confirm the accuracy of their tests in finding ancestral information and therefore should not be completely relied upon for discovering self-identity.

Nevertheless, people use DNA kits to reaffirm their beliefs about their identity. Eduardo, a Mexican-American man who initially identified as White Hispanic with Native American ancestry, discovered he was also part Jewish and Celtic, but later rejected his Celtic identity, explaining, “I can pass for a Jew, there’s no question about it. There’s no way I could pass for a Celtic, because I’m dark, and sort of fat, short.”<sup>8</sup> His reaction shows how genetic tests can reinforce what consumers want to believe. Many times, people pick the truths they want from their tests while rejecting others, just as Eduardo dismissed his Celtic ancestry based on his physical appearance.

Additionally, a multitude of factors beyond genetics, including family and culture, influence identity. Basing heritage purely on genetics ignores all other aspects of an individual’s identity. In the Native American community, many feel threatened by scientists telling them where they “really” originate from. Kim Tallbear, a member of the Sisseton-Wahpeton Oyate tribe, a researcher at the University of Texas at Austin, and the author of *Native American DNA: Tribal Belonging and the False Promise of Genetic Science*, asks, “We know who we are as a people, as an indigenous people, why would we be so interested in where scientists think our genetic ancestors came from?”<sup>9</sup> This sentiment shows how identity is more than genetics. Identity is also formed by childhood, environment, close relationships, and culture of a person. Ultimately, a genetic test should not confirm what makes up a person, especially since companies require more research to increase the accuracy of their results. Genetics constitute a very small part of self-identity, therefore remaining unreliable for capturing the full existence of an individual.

#### V. ACCURACY LIMITATIONS AND THE NEED FOR MEDICAL CONSULTATION

Genetic testing kits may contain inaccuracies and should not replace the consultation of medical experts. For instance, people should not fully rely on this technology for health information due to their inherent inaccuracy. The Food and Drug Administration (FDA) did not completely approve the use of genetic kits for health purposes; “in general, direct-to-consumer tests for non-medical, general wellness, or low risk medical purposes are not reviewed by the FDA before they are offered.”<sup>10</sup> Although the FDA does not approve some genetic testing kits for health information, they endorse companies such as 23andMe based on reliability, accuracy, and consumer comprehension.<sup>11</sup> The FDA states that “Results from this test should be confirmed with independent pharmacogenetic testing before making any medical decisions.”<sup>12</sup> These tests should help inform, not dictate, discussions with a healthcare provider.

#### VI. COST AND PRIVACY ISSUES

Opponents of DNA testing companies worry about the price of kits and privacy issues. Many adversaries of genetic kits claim that the cost of the technology is too expensive. However, most insurance companies will

cover the cost of genetic testing, and different types of reliable kits vary in price, starting as low as \$59. Opponents also point out privacy concerns and insufficient consumer data protection. While HIPAA (Health Insurance Portability and Accountability Act) and GINA (the Genetic Information Nondiscrimination Act of 2008) protect patient privacy, they are limited. The HIPAA Privacy Rule aims to protect the privacy of individually identifiable health information. HIPAA was designed to improve the portability of health data for administrative ease – companies outside of insurance and the delivery of health care are largely excluded from its requirements. It does not apply to companies unrelated to health care.<sup>13</sup> GINA is designed to prevent discrimination. Insurers and employers must adhere to its requirements. Despite their limitations, these federal acts, in addition to state-level legislation and industry initiatives like the Coalition for Genetic Data Protection, mark significant progress in addressing genetic privacy concerns.

#### VII. PSYCHOLOGICAL EFFECTS

Some may feel that genetic testing kits can carry detrimental psychological effects. Tests that reveal an increased risk of various genetic diseases may induce panic or anxiety in people. In medical venues, clinicians are more likely to address the emotional responses to reports, which is an essential part of delivering responsible genetic services. However, as ancestry and heritage companies do not deliver medical care, they are unlikely to properly emotionally support their customers. People need all the information necessary to make informed decisions about their health. Individuals should also consult a medical professional regarding their test results to help them better understand these outcomes. Although test results can elicit surprise and anxiety in consumers, they can also provide relief. Understanding genetic conditions earlier reduces uncertainty and helps a person take steps to avoid possible health issues.

#### VIII. CONCLUSION

In conclusion, genetic testing kits can enhance the quality of life by providing insight into health problems and ancestral lineage but should not dictate identity or substitute consulting medical experts. Opponents of genetic testing kits emphasize the high cost, privacy issues, and psychological effects of commercial DNA tests. The March 2025 bankruptcy filing by 23andMe highlights vulnerabilities in the genetic testing industry, raising concerns about the security of genetic data held by commercial entities. However, genetic testing provides people with a deeper understanding and awareness of potential health issues, enabling them to prevent and prepare for illnesses. These kits also offer reassurance by reducing the sense of uncertainty. Furthermore, publicly available genetic testing represents a remarkable innovation that continues to advance in both convenience and accuracy. In the future, genetic testing will play a pivotal role in health care by enabling tailored prevention strategies, early interventions, and personalized treatments, while addressing ethical and privacy concerns.

---

<sup>1</sup> Hugo, Kristin. "How Do DNA Test Kits Work?" *Newsweek*, Newsweek, 6 July 2018, [www.newsweek.com/how-do-dna-test-kits-work-difference-between-birthplace-and-heritage-1011066](http://www.newsweek.com/how-do-dna-test-kits-work-difference-between-birthplace-and-heritage-1011066).

<sup>2</sup> Regalado, Antonio. "More than 26 Million People Have Taken an At-Home Ancestry Test." *MIT Technology Review*, MIT Technology Review, 22 Aug. 2024, [www.technologyreview.com/2019/02/11/103446/more-than-26-million-people-have-taken-an-at-home-ancestry-test/](http://www.technologyreview.com/2019/02/11/103446/more-than-26-million-people-have-taken-an-at-home-ancestry-test/).

<sup>3</sup> “Genetic Testing.” *Mayo Clinic*, Mayo Foundation for Medical Education and Research, 14 Apr. 2020, [www.mayoclinic.org/tests-procedures/genetic-testing/about/pac-20384827](http://www.mayoclinic.org/tests-procedures/genetic-testing/about/pac-20384827).

<sup>4</sup> Stein, Rob. “Results of At-Home Genetic Tests for Health Can Be Hard to Interpret.” *NPR*, NPR, 18 June 2018, [www.npr.org/sections/health-shots/2018/06/18/609750963/results-of-at-home-genetic-tests-for-health-can-be-hard-to-interpret](http://www.npr.org/sections/health-shots/2018/06/18/609750963/results-of-at-home-genetic-tests-for-health-can-be-hard-to-interpret).

<sup>5</sup> Stewart, Kelly F., et al. “Behavioural changes, sharing behaviour and psychological responses after receiving direct-to-consumer genetic test results: a systematic review and meta-analysis.” *Journal of Community Genetics*, vol. 10, no. 2, 2 Jan. 2018, pp. 321–321, <https://doi.org/10.1007/s12687-017-0353-1>.

<sup>6</sup> Wendy D. Roth. “Genetic Ancestry Tests Don’t Change Your Identity, but You Might.” *The Conversation*, 19 Dec. 2024, [theconversation.com/genetic-ancestry-tests-dont-change-your-identity-but-you-might-98663](http://theconversation.com/genetic-ancestry-tests-dont-change-your-identity-but-you-might-98663).

<sup>7</sup> “Can 23andMe Identify Indigenous American Ancestry? – 23andme Customer Care.” *23andme*, [customer.23andme.com/hc/en-us/articles/202906870-Can-23andMe-Identify-Indigenous-American-Ancestry](http://customer.23andme.com/hc/en-us/articles/202906870-Can-23andMe-Identify-Indigenous-American-Ancestry).

<sup>8</sup> Roth.

<sup>9</sup> Eveleth, Rose. “Genetic Testing and Tribal Identity.” *The Atlantic*, Atlantic Media Company, 27 Jan. 2015, [www.theatlantic.com/technology/archive/2015/01/the-cultural-limitations-of-genetic-testing/384740/](http://www.theatlantic.com/technology/archive/2015/01/the-cultural-limitations-of-genetic-testing/384740/).

<sup>10</sup> Rotshenker-Olshinka, Keren, and Michael H. Dahan. “Fertility Care in the era of commercial direct-to-consumer home DNA kits: Issues to ponder.” *Journal of Assisted Reproduction and Genetics*, vol. 37, no. 3, 26 Feb. 2020, pp. 689–692, <https://doi.org/10.1007/s10815-020-01711-y>.

<sup>11</sup> Center for Drug Evaluation and Research. “Direct-to-Consumer Tests.” *U.S. Food and Drug Administration*, FDA, [www.fda.gov/medical-devices/vitro-diagnostics/direct-consumer-tests#list](http://www.fda.gov/medical-devices/vitro-diagnostics/direct-consumer-tests#list).

<sup>12</sup> Office of the Commissioner. “FDA Authorizes First Direct-to-Consumer Test for Detecting Genetic Variants That May Be Associated with Medication Metabolism.” *U.S. Food and Drug Administration*, FDA, [www.fda.gov/news-events/press-announcements/fda-authorizes-first-direct-consumer-test-detecting-genetic-variants-may-be-associated-medication](http://www.fda.gov/news-events/press-announcements/fda-authorizes-first-direct-consumer-test-detecting-genetic-variants-may-be-associated-medication).

<sup>13</sup> Clayton, Ellen Wright, et al. “The Law of Genetic Privacy: Applications, Implications, and Limitations.” *Journal of Law and the Biosciences*, vol. 6, no. 1, 14 May 2019, pp. 1–36, <https://doi.org/10.1093/jlb/lz007>.