



Consumer Federation of America

**MARKETING DIRECT-TO-CONSUMER
GENETIC TESTING:
ARE CONSUMERS GETTING WHAT THEY THINK
THEY ARE?**

(CONDENSED REPORT)

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Executive Summary

Direct-to-Consumer (DTC) genetic tests are widely promoted as a means for individuals to learn about their origins, find unknown relatives, and identify health traits. According to the MIT Technology Review, as many people purchased these tests in 2018 as in all previous years combined, and by the start of 2019, more than 26 million consumers had added their DNA to four leading commercial ancestry and health databases. Surprisingly given the sensitive nature of genetic testing, most DTC genetic tests are not reviewed by the government before they are marketed to confirm the claims made for them, their accuracy, or their validity.

With a grant from the Rose Foundation, Consumer Federation of America (CFA) studied the claims made for these tests, the information companies provide to consumers about the testing, the variance of results from one company to another, the up-selling that occurs, the terms of service, and the companies' privacy policies. We focused on six companies that commonly appeared in searches for DTC genetic testing: 23andMe, Ancestry, FamilyTreeDNA, HomeDNA, LivingDNA, and MyHeritage. As the test subject, I purchased the companies' basic ancestry kits online in March 2020, took my samples on one day that month, and sent them in.¹ Nick Roper, Administrative and Advocacy Associate at CFA, assisted me with research.

Our intention is not to advise consumers whether to purchase these tests or to rate the companies. The aim of the project is to help educate consumers about DTC genetic tests and make recommendations for better informing and protecting people who use these services.

What We Found

- 1. The results of ancestry tests are not 100 percent accurate, vary from company to company, and may change over time.** DTC genetic testing companies analyze individuals' genes and then look for their genetic links to certain geographic areas – the parts of the world from which their ancestors likely originated. If DNA matching is included in the service, they also look for people who may be related to each other. The results the companies produce are *estimates* based on comparing an individual's data to that of other customers in their databases. Since not all companies have the same customers, the pools of data they have differ, as do the algorithms they use to create their estimates. Some companies include results for Jewish ethnicity, others do not. Because of these differences, ancestry results vary from one company to another. Furthermore, as companies add more customers and collect more data, individuals' ancestry results may change. In addition, the terms DTC genetic testing companies use to describe the geographic areas from which individuals' DNA originated are not standardized and can change as the companies collect more data and are able to make more precise estimates.

¹ I retook the Living DNA test in early May because the first sample was not sufficient.

2. **Access to historical records, if offered, is extra.** Some ads for DTC genetic testing services imply that customers will learn the addresses where their ancestors lived, their occupations, and other details about their lives. Access to census data, birth and death records, newspaper stories, military service records, and other historical documents is not included in basic ancestry testing services, however. If it's available, it is an upgrade or a separate service, for an extra charge.
3. **DTC genetic health tests may be helpful but are not conclusive.** Some DTC genetic testing companies offer information to individuals about how their genes may link to certain health conditions, from the likelihood that they will be overweight to the risk of developing specific diseases. As with ancestry, these test results are *estimates* that can vary from one company to another and may change over time as more data is amassed and scientific research makes more progress. Furthermore, the tests may result in false positives or false negatives. Moreover, genetic tests for specific health risks cannot determine with absolute certainty whether someone will develop a disease or condition, since environment and lifestyle can be contributing factors.
4. **The limitations of ancestry and health tests aren't always made clear.** While some advertisements for DTC genetic health tests include disclaimers that the results may vary and should not be used for diagnosis or treatment, this information is in fine print that is difficult to see. Disclaimers on the websites about the accuracy of ancestry and health tests are sometimes buried in the terms of service, which consumers are unlikely to read.
5. **Warnings about unexpected results may not be easy to find or provided at all.** The results of genetic tests might be welcome, but they could also be upsetting. People may be excited to discover relatives they didn't know they had, but that could create family stress and financial issues. Furthermore, they might discover that they're not biologically related to someone they thought they were, or that they may have a risk of a serious health condition. Some DTC genetic testing companies warn about unexpected results, others do not. In some cases, this important information is buried in the terms of service. Advice about how to deal with these situations is not always provided.
6. **DTC genetic testing companies encourage individuals to participate in research.** Research for historical or scientific purposes provides the companies with more data to work with and can make their test results more accurate. They may also make money from research projects. Individuals are encouraged to participate in research but they are not automatically enrolled; it is a separate agreement. While research may benefit individuals and society as a whole, there can also be risks, including the possibility of data breaches and being personally identified even in anonymized research results. Furthermore, participants in research may find the results unexpected and uncomfortable.

- 7. Up-selling is a common feature of DTC genetic testing services.** Customers are likely to receive offers for expanded ancestry services, information about personal “traits,” health risk tests, access to historical records, personalized books, and even genetic tests for pets. Some offers may be for “free trials” – for instance, to access historical information at no charge for a certain period of time, after which the customers will be charged unless they canceled in time. The terms of free trial offers are not always made clear before the enrollment page. Customers may be solicited by email, phone, or ads that pop up in their portals on the companies’ websites. Some companies provide customers with settings in their accounts to control emails, but not other forms of advertising.
- 8. Customers may not realize their personal information could be shared with others.** DTC genetic testing companies are not covered by privacy requirements that apply to healthcare providers, and federal law only limits access and use of individuals’ genetic information by employers and health insurers. Only a handful of states provide broader privacy protections. In the absence of legal constraints, the companies are free to share customers personal information and allow invisible trackers on their websites to collect information about customers online activities (though they cannot see their tests results). They may also share customers’ data with law enforcement under certain circumstances. Some companies have adopted voluntary best practices that require customers’ explicit consent to sharing particularly sensitive information, such as their genetic data. Their privacy policies are not always clear, however.
- 9. Customers’ personal information may not disappear when they close their accounts.** When DTC genetic testing customers close their accounts, they are no longer able to access the information in their portals, their test results will not be updated, and their DNA matching will stop. That does not necessarily mean that their personal information will disappear. If customers have shared or posted their information where others can see it, it can’t be removed. Information they provided for research will be retained if those projects are completed or, in some cases, are still underway. Furthermore, DTC genetic testing companies may be required to keep some personal information, including genetic samples, to comply with laws and certification requirements. Customers may need to separately ask for their genetic samples to be destroyed.
- 10. Most DTC genetic testing companies restrict consumers’ rights and recourse.** They often disclaim any warranties or liability in their terms of service and force consumers to go to binding arbitration in the event of a dispute, unilaterally waiving their right to seek redress in court, particularly through class-action lawsuits. When consumers can sue, the terms of service may require them to do so in a distant state, or even in another country.

Recommendations

- 1. DTC genetic testing companies should refrain from making specific accuracy claims.** In its terms of service, LivingDNA says: “Although we will make every effort to provide a reasonable level of accuracy, our DNA test results, and any reports should be viewed as a guide or indicative only. The accuracy and precision of the reports that we provide to you will in part be dependent on the pool of DNA data that we have available to compare your data with.”² We think this is the right way to describe the accuracy of the information that DTC genetic testing companies provide because specific claims of accuracy rates have the capacity to mislead consumers.
- 2. The Federal Trade Commission should study disclaimers in television advertisements.** Disclaimers that are provided in fleeting fine print during commercials for DTC genetic health tests do not help consumers understand the limitations of those services. This problem is not unique to DTC genetic tests, however; important information about products and services is routinely hidden from consumers in television advertisements by making it virtually impossible to read it.
- 3. Important information should not be buried in the terms of service.** Companies’ terms of service are intended to provide them with legal cover but do nothing to inform consumers. Few people read them, and even fewer are likely to understand them. Important information for consumers should not appear *only* in the terms of service. This is another area that would be useful for the Federal Trade Commission to study.
- 4. Key information about DTC genetic tests should be provided in a standardized format.** This could be in the form of a prominent disclosure, “What You Should Know about Genetic Testing Services,” on DTC genetic testing companies’ homepages, and on the packages if their kits are sold in stores. The language of the disclosure should be tested to ensure that consumers understand it. These key points should be covered:
 - Tests for ancestry look for your genetic links to certain geographic areas where your ancestors may have come from. The results are estimates based on comparing your data to that of other customers and are not guaranteed to be 100 percent accurate.
 - Your results may change over time as more information is added to our databases.
 - Access to census data, birth and death records, newspaper stories, military service records, and other historical documents is not included in basic ancestry testing services and requires paying an additional fee or buying a DNA testing service that includes it.³

² <https://livingdna.com/legal/Living-DNA-terms-of-service>, Part 3. 1.

³ This would be included if access to historical documents is offered; if not, companies should not imply that it is.

- Our health tests can provide you with helpful information about how your genes may link to certain health conditions. The results are estimates and may change over time as we gather more data and scientific research makes more progress. Health risk tests may produce false results and can't predict with certainty whether you will develop a specific disease or condition, since environment and lifestyle can also play roles in your health. These tests should not be used to diagnose or treat specific conditions. Consult with your doctor before taking any action on the basis of health test results.
- You could receive test results that are unexpected. Some may be welcome, but some results about your origin, your relatives, or your health could be upsetting. We provide advice about how to deal with unexpected results.⁴

5. Customers should have control of marketing for additional products and services.

DTC genetic testing customers should be provided with easy-to-use controls in their account settings to choose whether to receive solicitations for additional products and services and how those offers will be made to them, including on the website.

6. The terms of free trial offers should be provided before the enrollment page.

Consumers should be clearly told exactly what the service will be, how much they will be charged if they continue after the trial period ends, and the deadline for canceling if they want to avoid charges. No personal information should be collected before enrollment.

7. Information about privacy should be prominent and easy to read. It is not enough to simply have a link to the privacy policy at the bottom of the homepage. DTC genetic testing companies should bring the importance of privacy to consumers' attention and encourage them to read the privacy policies. This could be done as part of the standardized disclosures we suggested or separately on companies' homepages. Privacy policies should be formatted and written to make them easy to read and understand.

8. Strong privacy protections should be enacted in the states and at the federal level.

The U.S. lags behind most other developed nations in providing comprehensive privacy protections. Companies' use and sharing of individuals' personal information should be limited to certain permissible purposes. Law enforcement should only be allowed to obtain individual's personal information pursuant to a valid legal process. Furthermore, the law should bar individuals from being discriminated against on the basis of their data.

9. Genetic samples should be automatically destroyed when customers close their accounts.







It should not be necessary for customers to make a separate request to have their genetic samples discarded. If the samples must be retained for legal or certification purposes, they should be de-identified and discarded as soon as permitted. DTC genetic testing companies should make their policies regarding data deletion clear to customers.

⁴ Not all the DTC genetic testing companies we studied provided this type of advice; we encourage them to do so.

10. Congress should prohibit “forced arbitration” in *all* consumer contracts.

Denying individuals the basic right to seek redress in court prevents them from effectively enforcing their rights and changing company practices that harm them and others.

Clarity of Privacy Policies

| | | |
|---------------|---|---|
| 23andMe |  | Has overview, table of contents with embedded links, definitions section, well-organized, simple language |
| Ancestry |  | Has overview, table of contents with embedded links, well-organized, simple language; no definitions but some terms explained |
| FamilyTreeDNA |  | No overview, table of contents or definitions, though some terms explained, relatively easy to read but format and language could be improved |
| HomeDNA |  | No overview, table of contents or definitions, not well-organized, dense paragraphs, language hard to read and confusing |
| LivingDNA |  | Has overview, table of contents but no links, no definitions though some terms explained, relatively easy to read but language and format could be improved |
| MyHeritage |  | Has overview, no table of contents or definitions, though some terms explained, relatively easy to read but language and format could be improved |

Using and Sharing Customers’ Genetic Data for Marketing

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|---------------|---|
| 23andMe | Company and service providers do not use genetic data for targeted marketing without customer’s consent |
| Ancestry | Company does not share genetic data with marketers without customer’s consent, will not use genetic data for own marketing without customer’s consent |
| FamilyTreeDNA | Company does not share genetic data with marketers without customer’s consent, not clear if it uses genetic data for its own marketing |
| HomeDNA | Not clear if company uses or shares genetic data for marketing and if customer’s consent is required to do so |
| LivingDNA | Does not appear that company uses or shares genetic data for marketing, will ask for customer’s consent to use it for purposes other than to provide services |
| MyHeritage | Company does not share genetic data for marketing without customer’s consent, does not appear to use genetic data for its own marketing but could be clearer |

*Note that some companies do not consider offering additional products or services to customers within their websites “marketing.”

Sharing Customers' Personal Information with Law Enforcement

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|---------------|--|
| 23andMe | May disclose customers' personal information in response to "lawful requests," link to transparency reports |
| Ancestry | Does not allow law enforcement to use customers' personal information to investigate crimes or identify remains, court order or search warrant required to consider requests for customers' personal information, link to transparency reports |
| FamilyTreeDNA | Permits law enforcement access to genetic database to identify remains or perpetrators of homicides or sexual assaults, no link to transparency reports |
| HomeDNA | May disclose customers' personal information to comply with "relevant laws" or subpoenas or warrants, no link to transparency reports |
| LivingDNA | Does not provide customers' personal information unless compelled to do so by court order, subpoena or regulator, no link to transparency reports |
| MyHeritage | Will not share genetic information unless required by court order or subpoena, no link to transparency reports |

Conclusion

DTC genetic testing can provide useful insights for individuals about their origins and health. It does have limitations in terms of the accuracy and extent of the information it can provide. That is why DTC genetic testing companies often describe their services as being intended for "educational" and "recreational" purposes. Since by its very nature genetic testing is highly personal, it is important for consumers to consider the impact the results may have on them and their families.

According to a recent news article,⁵ fewer people are buying DTC genetic tests due to concerns about privacy and because the market is becoming "tapped out" – if you have already taken an ancestry test, you are not likely to buy another. The article speculates that these companies are shifting to promoting health-related tests. Health-related tests raise heightened privacy concerns, however, and because the results may not be accurate they should not be used to diagnose or treat health conditions.⁶

Another cautionary note: it is also possible that fraudsters may use offers of health-related genetic testing to consumers in order to bilk Medicare or steal their sensitive personal information.⁷ Consumers should check the reputations of genetic testing companies with the Better Business Bureau, <https://www.bbb.org/>, and other credible sources of complaint information, keeping in mind that no complaints is not a guarantee that a company is legitimate.

⁵ Christina Farr, "Consumer DNA testing hits a rough patch: Here's how companies like Ancestry and 23andMe can survive," CNBC (February 9, 2020, updated August 26, 2020), available at <https://www.cnbc.com/2020/02/07/how-dna-testing-companies-like-ancestry-and-23andme-can-survive.html>.

⁶ See Shaoni Bhattacharya, "Experts speak out on direct-to-consumer genetic testing," BioNews (July 22, 2019), available at https://www.bionews.org.uk/page_143986.

⁷ See Bob Thomas, "Genetic testing: the next big area for fraud?" Stat (June 7, 2019), available at <https://www.statnews.com/2019/06/07/genetic-testing-fraud/>.

Genetic testing is a complex subject, and while some DTC genetic testing companies provide extensive educational information on their websites, the degree to which people are likely to delve into it will vary. DTC genetic testing companies should be careful about the claims they make in their advertisements and on their websites, which could have the capacity to mislead consumers. We believe a standardized disclosure of key information could be a helpful educational tool. Important disclosures should not be buried in the terms of service.

Because of the sensitive nature of the personal information DTC genetic testing companies collect, they should make information about privacy more prominent and ensure that their privacy policies are clear and easy to read and understand. They should also provide customers with easy-to-use controls for marketing and deleting their data.

It is unfair for agreements for DTC genetic testing, or for any consumer products or services, to deny individuals the ability to take legal action if they believe their rights have been violated or they have been treated unfairly.

Finally, it is crucial to enact strong laws at the state and federal level to protect the privacy and security of consumers' personal information and prevent its use in ways that are discriminatory.

To view the full report, click [here](#).

9 Questions and Answers about DTC Genetic Testing

Would you like to learn more about where your ancestors came from? Find long-lost relatives? Know whether you're likely to develop certain health problems? This is the kind of information that direct-to-consumer (DTC) genetic testing companies promise. You can buy a test kit online or in a store, without a doctor's orders. Just follow the directions to swab the inside of your cheek or spit into a tube and send in your sample as instructed, and within a couple of weeks you'll get the results. If you're thinking about taking one of these tests or giving a kit to someone else, it's important to understand what the tests reveal, how your personal information is handled, and how the test results could affect you and your family.

1. What do you get when you take a DTC genetic test?

Your genes are the DNA instructions you inherit from your mother and father. They are a large part of what makes you “you.” DTC genetic tests for ancestry look for your genetic links to certain geographic areas – the parts of the world your ancestors likely came from, and perhaps even more specifically the countries and areas within them. You may also get information about Jewish origins. Some DTC genetic testing companies also provide DNA matches – people who may be related to you. Health-related DTC genetic tests may provide helpful information about nutrition, skincare, and weight based on your genetic make-up. Some tests predict the risks of developing specific health conditions or diseases.

2. How accurate is this information?

The information a DTC genetic testing company provides is an *estimate* based on comparing your data to that of other customers in its database. Predictions about DNA matches are generally more accurate for close family members than for distant ones. When the company adds more customers and collects more data, your test results may change. With health tests, new scientific research may also change the results. Since DTC genetic testing companies don't all have the same customers and don't use the same formulas to produce their ancestry and health reports, one may provide you with different information than another.

3. Could DTC genetic tests produce unexpected results?

The information you receive as a result of genetic tests may be welcome, but it could also be upsetting. You may be excited to discover unknown relatives, but that could create family stress and financial issues. You could also learn that your origins are not what you thought, or that you are not biologically related to someone you thought you were, or that you're at risk of a serious health problem. Some DTC genetic testing companies offer advice about unexpected results, but not all do. You can find organizations online that provide suggestions for handling these situations.

4. Will you get historical information about your ancestors?

Based on some ads for DTC genetic testing services, you may assume that you'll be able to learn where your ancestors lived, their occupations, and other details about their lives. Access to census records, birth and death records, immigration records, newspaper articles, military records and other historical information is not included in the basic ancestry services, however. If the company offers this information, it is an upgrade or a separate service, for an extra charge. You may have access to additional information about your ancestors posted by other people. But you may have to go to more expense, and do a lot more work yourself, to get a more complete picture of your ancestors.

5. What action should you take based on the results of health-related DTC genetic tests?

These tests are *not* intended to diagnose or treat health conditions. The information they produce is an *estimate* based on the data the company has about how your genes link to health conditions. It's also important to know that these tests can produce false positives or false negatives, and they can't predict health risks with absolute certainty because your environment and lifestyle can also affect your health. Always check with your doctor before taking any action based on DTC genetic health tests.

6. What should you do if the testing company asks you to participate in research?

DTC genetic testing companies may conduct their own research or work with research partners for scientific or historical purposes. Research provides the companies with more data to work with, which can make the information they provide to customers more accurate, and they may also make money from research projects. Participation is strictly voluntary and you'll be asked to sign a separate agreement for it. While research may benefit you and others, there are risks, including data breaches, being identified even if you are "anonymous," and receiving results that may be unexpected or uncomfortable.

7. Will the company try to sell you other products or services?

Once you become a customer, you'll likely receive offers from the company for expanded ancestry services, information about personal "traits," health-related tests, access to historical records, personalized books, and even genetic tests for pets. Some offers may be for "free trials" – for instance, to access historical information for a certain period of time at no charge. Before you sign up, look for details about how much the service will cost if you continue to use it after the trial period ends and when you must let the company know if you don't plan to continue to avoid being charged. Offers may come by email or phone, or pop up in your portal on the company's website. You may have controls in your settings to control emails, and by law you always have the right to stop receiving marketing emails and calls.

8. Will the company share your personal information with others?

The company may use your personal information for its own marketing and share it with other companies. It may ask for your consent to use or share particularly sensitive data, such as your genetic information. Law enforcement may be able to get your data, including genetic information, from the company under certain circumstances. The company may also allow invisible trackers on its website to collect information about what you do there and elsewhere on the internet (though they can't see the information in your password-protected portal) for advertising and other purposes. Check with your state or local consumer agency about any privacy rights that apply, and read DTC testing genetic companies' privacy policies carefully before buying their services.

9. What other privacy issues should you consider with DTC genetic testing?

You can control what other customers can see about you and how they can communicate with you on the company's website. If you use social media in connection with the service, be sure your settings on the social media platform don't allow the genetic testing company to collect your personal information. Take care if you post or share information with others, or upload your genetic data to another website, since once it's out there you may not be able to retrieve it. Be aware that if you close your genetic testing account, you may need to take a separate step to request that your genetic sample be destroyed, and the company may still keep some information about you if necessary for legal purposes.