



Consumer Federation of America

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

Susan Grant
Director of Consumer Protection and Privacy
Consumer Federation of America

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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
 - 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

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.

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.

What DTC Genetic Tests Are and How They Work

According to the National Human Genome Institute, genetic testing “uses laboratory methods to look at your genes, which are the DNA instructions you inherit from your mother and your father.”⁵ The Centers for Disease Control (CDC) explains that there is a difference between clinical genetic tests, which are typically ordered by a doctor for a specific medical reason, and direct-to-consumer (DTC) genetic tests, which are “usually purchased by healthy individuals who are interested in learning more about traits like ancestry, responses to medications, or risk for developing certain complex conditions.”⁶

When health care providers order genetic tests, they interpret the results and use them to make recommendations to their patients. But with DTC genetic tests, there is usually no health care provider involved. Instead, these test kits are readily available for consumers to buy online and in some stores and are designed to be simple to use at home: 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 see the results posted in a password-protected portal on the company’s website.

The U.S. National Health Library (NHL) provides simple, objective information about the types of tests that are available, how they work, what to look for, and what to look out for. There are also links to information from other credible sources.⁷

According to the NHL, the major types⁸ of DTC genetic tests are:

Disease risk and health

The results of these tests estimate your genetic risk of developing several common diseases, such as celiac disease, Parkinson disease, and Alzheimer disease. Some companies also include a person’s carrier status for less common conditions, including cystic fibrosis and sickle cell disease. A carrier is someone who has one copy of a gene mutation that, when present in two copies, causes a genetic disorder. The tests may also look for genetic variations related to other health-related traits, such as weight and metabolism (how a person’s body converts the nutrients from food into energy).

Ancestry or genealogy

The results of these tests provide clues about where a person's ancestors might have come from, their ethnicity, and genetic connections between families.

⁵ <https://www.genome.gov/FAQ/Genetic-Testing>.

⁶ https://www.cdc.gov/genomics/gtesting/genetic_testing.htm.

⁷ At <https://medlineplus.gov/genetics/understanding/dtcgeneticstesting/>.

⁸ From <https://medlineplus.gov/genetics/understanding/dtcgeneticstesting/dtctesttypes/>.

Kinship

The results of these tests can indicate whether tested individuals are biologically related to one another. For example, kinship testing can establish whether one person is the biological father of another (paternity testing). The results of direct-to-consumer kinship tests, including paternity tests, are usually not admissible in a court of law.

Lifestyle

The results of these tests claim to provide information about lifestyle factors, such as nutrition, fitness, weight loss, skincare, sleep, and even your wine preferences, based on variations in your DNA. Many of the companies that offer this kind of testing also sell services, products, or programs that they customize on the basis of your test results.

It's important for consumers to understand the benefits, risks and limitations of DTC genetic tests, especially since they can purchase and use these tests without medical supervision or the advice of a genetics counselor. The NHL describes⁹ them as follows:

Benefits

- Direct-to-consumer genetic testing promotes awareness of genetic diseases.
- It provides personalized information about your health, disease risk, and other traits.
- It may help you be more proactive about your health.
- It does not require approval from a healthcare provider or health insurance company.
- It is often less expensive than genetic testing obtained through a healthcare provider.
- DNA sample collection is usually simple and noninvasive, and results are available quickly.
- Your data is added to a large database that can be used to further medical research. Depending on the company, the database may represent up to several million participants.

Risks and limitations

- Tests may not be available for the health conditions or traits that interest you.
- This type of testing cannot tell definitively whether you will or will not get a particular disease.
- Unexpected information that you receive about your health, family relationships, or ancestry may be stressful or upsetting.
- People may make important decisions about disease treatment or prevention based on inaccurate, incomplete, or misunderstood information from their test results.

⁹ From <https://medlineplus.gov/genetics/understanding/dtcgeneticstesting/dtcrisksbenefits/>.

- There is currently little oversight or regulation of testing companies.
- Unproven or invalid tests can be misleading. There may not be enough scientific evidence to link a particular genetic variation with a given disease or trait.
- Genetic privacy may be compromised if testing companies use your genetic information in an unauthorized way or if your data is stolen.
- The results of genetic testing may impact your ability to obtain life, disability, or long-term care insurance.

How DTC Genetic Tests Are Regulated

DTC genetic tests are not heavily regulated. Some are reviewed by the U.S. Food and Drug Administration (FDA) before they are marketed, but not all are. As the FDA explains:

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. Direct-to-consumer tests for moderate to high risk medical purposes, which may have a higher impact on medical care, are generally reviewed by the FDA to determine the validity of test claims.¹⁰

The ancestry tests that I took are not reviewed by the FDA for the validity of the claims they make, their accuracy, or their reliability. DTC genetic tests that indicate people’s propensity for certain traits, such as weight gain, snoring, or freckles, or how particular diets and exercises could help them lead healthier lives, are also not subject to FDA review. DTC tests for health risks may require FDA pre-market approval, however. In 2017, the agency granted the first such authorization to 23andMe for genetic tests for certain diseases and conditions.¹¹ The FDA made clear that it intended to exempt the company from having to apply for pre-market approval for additional tests of that nature and would do the same for other companies using similar technology. In 2019, the FDA sent a warning letter to Genova Genomics Laboratory for illegally marketing genetic tests to predict patients’ responses to specific medications without prior review for safety and effectiveness.¹²

The Federal Trade Commission (FTC) protects consumers from unfair or deceptive acts or practices.¹³ Typically, the FTC takes action against businesses when they make false or misleading claims about their products or services or fail to disclose information that would be important in consumers’ purchasing decisions. The FTC also brings cases involving false or misleading claims about the privacy and security of the personal information that companies

¹⁰ See <https://www.fda.gov/medical-devices/vitro-diagnostics/direct-consumer-tests>.

¹¹ See FDA press release (April 6, 2017) at <https://www.fda.gov/news-events/press-announcements/fda-allows-marketing-first-direct-consumer-tests-provide-genetic-risk-information-certain-conditions>.

¹² See FDA press release (April 4, 2019) at <https://www.fda.gov/news-events/press-announcements/fda-issues-warning-letter-genomics-lab-illegally-marketing-genetic-test-claims-predict-patients>.

¹³ 15 U.S.C. §45 (a) (1), available at <https://www.law.cornell.edu/uscode/text/15/45>.

collect and failure to adequately secure that data. We are not aware of any actions the FTC has taken against DTC genetic testing companies to date. In 2019, the FTC issued tips for companies that sell DTC genetic tests to encourage them to adopt good privacy practices and follow basic truth-in-advertising principles.¹⁴ As part of this project we look at how well the DTC test companies appear to be complying with that advice.¹⁵

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) sets requirements for protecting the privacy and security of health information,¹⁶ including genetic information. It does not apply to DTC genetic testing companies, however, since they are not considered healthcare providers, health plans, or healthcare data clearinghouses.¹⁷ The results of DTC genetic tests are covered by HIPAA if they are transmitted to a covered entity and become part of an individual's health records.

Another federal law, the Genetic Information Nondiscrimination Act of 2008 (GINA),¹⁸ regulates the use of genetic information by employers and insurers. Though it doesn't specifically refer to DTC genetic tests, the results of those tests are covered as genetic information. GINA prohibits employers from requesting, requiring, or purchasing genetic information and from using genetic information as the basis for failing or refusing to hire someone, discharging an employee, or discriminating against an employee. It also bars health insurance providers from requesting, requiring, or using a person's genetic information for underwriting purposes. GINA does not apply to life insurance, disability insurance, or long-term care insurance, however. Furthermore, it does not restrict what DTC genetic testing companies or third parties do in terms of sharing consumers' data; it simply prohibits employers and health insurers from requesting or requiring genetic information and using it for specific purposes.

State and local laws concerning privacy, security, data breaches, and consumer protection apply to DTC testing companies. In addition, some states have enacted specific genetic testing privacy protections, which are summarized in the appendix of a white paper from Consumer Reports.¹⁹ These laws generally limit the collection, use and disclosure of individuals' genetic information. The California legislature recently approved a bill²⁰ which would have required a DTC genetic testing company or any other company that "collects, uses, maintains, or discloses genetic data collected or derived from a direct-to-consumer genetic testing product or service, or provided

¹⁴ Elisa Jillson, "Selling genetic testing kits? Read on." Federal Trade Commission (March 21, 2019), available at <https://www.ftc.gov/news-events/blogs/business-blog/2019/03/selling-genetic-testing-kits-read>.

¹⁵ State and local consumer protection laws may also apply.

¹⁶ 45 CFR Part 164 – Privacy and Security, <https://www.law.cornell.edu/cfr/text/45/part-164>.

¹⁷ 45 CFR §106.102, <https://www.law.cornell.edu/cfr/text/45/160.102>.

¹⁸ Public Law 110-233 (May 21, 2008), available at <https://www.congress.gov/110/plaws/publ233/PLAW-110publ233.pdf>.

¹⁹ Justin Brookman, Director, Privacy and Technology Policy, *Direct-to-Consumer Genetic Testing: The Law Must Protect Consumers' Genetic Privacy*, Consumer Reports (June 2020), available at <https://advocacy.consumerreports.org/wp-content/uploads/2020/07/DTC-Genetic-Testing-White-Paper-4.pdf>.

²⁰ See http://www.leginfo.ca.gov/faces/billTextClient.xhtml?bill_id=201920200SB980.

directly by a consumer” to provide clear notice about its data practices and obtain consumers’ express consent to collect, use, or disclose their data. It would have prohibited discrimination on the basis of one’s data, and also provided that an agreement obtained through use of “dark patterns” (defined as a user interface designed or manipulated with the substantial effect of subverting or impairing user autonomy, decision making, or choice) would not constitute consent. Unfortunately, the California Governor vetoed the legislation.

Marketing for DTC Genetic Tests and Other Products and Services

In their advertisements and on their websites, DTC genetic testing companies tout their ability to determine your origins, find relatives, and provide health insights. Using the free search feature on ispot.tv,²¹ a company that sells analytical information about advertisements on television, we found commercials for 23andMe, Ancestry, and MyHeritage. We have selected some examples, grouping them into the three categories cited above, and will discuss each in turn.

Determining Your Origins

In regard to ancestry tests, the NHL explains how they work²² and provides this cautionary note:

Genetic ancestry testing has a number of limitations. Test providers compare individuals' test results to different databases of previous tests, so ethnicity estimates may not be consistent from one provider to another. Also, because most human populations have migrated many times throughout their history and mixed with nearby groups, ethnicity estimates based on genetic testing may differ from an individual's expectations. In ethnic groups with a smaller range of genetic variation due to the group's size and history, most members share many SNPs,²³ and it may be difficult to distinguish people who have a relatively recent common ancestor, such as fourth cousins, from the group as a whole.”²⁴

These nuances are difficult to convey in television commercials such as these:

<https://www.ispot.tv/ad/wyTd/23andme-100-nicole-journey-song-by-gertrude-lawrence>

<https://www.ispot.tv/ad/wppp/ancestrydna-testimonial-kyle>

<https://www.ispot.tv/ad/wKqV/ancestrydna-kim>

<https://www.ispot.tv/ad/AQPp/myheritage-dna-instant-discoveries>

²¹ <https://www.ispot.tv/>

²² See <https://medlineplus.gov/genetics/understanding/dtcgeneticstesting/ancestrytesting/>.

²³ For an explanation of SNPs, go to the University of Utah’s Genetics Science Learning Center, <https://learn.genetics.utah.edu/content/precision/snips/>.

²⁴ See <https://medlineplus.gov/genetics/understanding/dtcgeneticstesting/ancestrytesting/>.

Based on my own experience, I wouldn't necessarily trade in my lederhosen for a kilt, as Kyle jokes about doing in the Ancestry ad that features him.

I believed that my mother's side of the family was from England and Ireland and that my father's family were Jews from what is now Ukraine. The results I got largely bore that out, though they were not consistent.

Here are the results that refer in one way or another to various parts of the British Isles²⁵:

| | |
|----------------------|--|
| 23andMe | 34.6 % British and Irish |
| Ancestry | 9% England and Northwestern Europe (was 21 % England, Wales and Northwestern Europe, changed on 9/18/20) 3% Wales 20 % Ireland (was 22% Ireland and Scotland, changed on 9/18/20) 14% Scotland |
| FamilyTreeDNA | 34 % British Isles |
| HomeDNA | 16.1 % Fennoscandia (The area known as Fennoscandia encompasses the countries of Norway, Sweden, Finland). Origin: Peaks in Iceland and Norway and declines in Finland, England, and France. 14.8 % Southern France. Origin: Peaks in south France and declines in north France, England, Orkney islands, and Scandinavia. 12.1 % Orkney Islands. Origin: Peaks in the Orkney islands and declines in England, France, Germany, Belarus, and Poland. |
| LivingDNA | 51.1 % Great Britain and Ireland |
| MyHeritage | 31.7 % Irish, Scottish, and Welsh |

It is difficult to compare the results from company to company because they don't use standardized descriptions for the geographic areas from which consumers' DNA originated. Also, as noted in the chart, my results from Ancestry changed significantly between March and September, 2020. But it is probably safe to say that somewhere between a third and half of my DNA comes from the British Isles. The rest is mostly from other parts of Europe, and those results also vary somewhat, both in how they are described and the percentages. Some companies provide more detailed breakdowns; for example, 23andMe says of the .9 percent of my origins in Southeastern Europe, .6 percent is Spanish and Portuguese. Some even specify particular counties or cities. The percentages aren't always provided in these breakdowns.

There were some rather surprising results: HomeDNA says that 10.8 percent of my DNA originated in Southeastern India, 4.4 percent in Northern India, and 4.3 percent in Arabia; LivingDNA says nearly 3 percent originates from Arabia; and Ancestry says I am also tied to additional communities of French settlers in Quebec.

²⁵ As of September 18, 2020.

As for my Jewish ethnicity, these are the results:

| | |
|---------------|---|
| 23andMe | 50 % Ashkenazi Jewish |
| Ancestry | 50 % European Jewish (was 57% but changed on 9/18/20) |
| FamilyTreeDNA | 44 % Ashkenazi Jewish |
| MyHeritage | 49.4 % Ashkenazi Jewish |

HomeDNA and LivingDNA did not mention anything about my Jewish origins. Note that my Ancestry results recently changed by 7 percent.

Some companies make specific accuracy claims on their websites, others provide much more qualified information, and some disclaim any guaranty of accuracy:

- 23andMe says, “Ancestry percentages are derived from our powerful, well-tested system that provides you with ancestry estimates down to the 0.1%.”²⁶
- Ancestry says, "With current technology, AncestryDNA has, on average, an accuracy rate of over 99 percent for each marker tested.”²⁷ This is further qualified, however, in a lengthy explanation that follows about ethnicity estimates.
- FamilyTreeDNA does not appear to make sweeping accuracy claims on its website. In an FAQ for its family ancestry product it says, “People sometimes feel their results are not accurate because they do not see a specific country or population reported. Please keep in mind that myOrigins uses regional percentages (not nationality/specific countries), as DNA mutates regionally rather than across man-made borders. It is also common for some individuals not to see certain reference populations, as they may not have received enough genetic ‘markers’ for that particular population throughout the generations.”²⁸
- HomeDNA says, “The level of accuracy depends on your family history. If your parents are from the same place and share relatively homogeneous gene pools, the test can trace both their DNA signatures to their country of origin 81% of the time. GPS Origins correctly predicts at least one parent to the correct country of origin 96% of the time. If both your parents are unmixed, GPS Origins can predict migration pinpoints to the correct country 90% of the time. In a study of people from across the world, the migration routes generated from the GPS Origins algorithm predicted continental origins with 98% accuracy, assigned 83% of the individuals to their country of origin, and, where applicable, 66% of them to their regional locations. If your ancestors were from Western Europe and your parents came from the same region, not moving far from the place they came from, the test will place your DNA signature within 50 miles of its true origin, and often closer. Your results show the origin as a pinpoint on a map. Any margin of error

²⁶ <https://www.23andme.com/howitworks/>.

²⁷ <https://www.ancestry.com/lp/genetic-testing/ancestrydna-test-accuracy>.

²⁸ <https://www.familytreedna.com/products/family-finder>, What if myOrigins results are not what I expected?

appears as a circle around the point. The smaller the circle, the more accurate the result. The accuracy also depends on the size of the reference population in a given area; the larger the reference group, the more accurate the results.”²⁹

- LivingDNA does not appear to make claims on its website about the accuracy of its ancestry tests. In fact, in the terms of service it explains, “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.”³⁰
- MyHeritage disclaims any guarantee of accuracy, saying in its terms of service, “We make no warranties, express or implied, as to the DNA Results and DNA Reports or to the accuracy, reliability, comprehensiveness, completeness, quality, currency, error-free nature, compatibility, security or fitness for purpose of the Website or the DNA Services or the DNA Reports.”³¹

Most consumers would probably assume, as I did, that the information provided as a result of their tests would be highly accurate, consistent from one company to another, and unchanging. Ancestry even encourages people to “confirm” their ancestral roots by taking its tests and then travel to their places of origin to “walk in your ancestor’s footsteps,”³² and 23andMe has partnered with Airbnb to promote “heritage travel.”³³

But before you buy that plane ticket, it is important to realize that your ancestry results are derived by comparing your data to that of the other customers in the DTC genetic testing company’s database. In a 2017 blog about its new ethnicity analysis, MyHeritage explained how it improved the precision of its results through a project involving 5,000 users who were chosen “by virtue of their family trees exemplifying consistent ancestry from the same region or ethnicity for many generations.”³⁴

As DTC genetic testing companies add more people to their databases and glean more information from their family trees and other content customers provide, they have more to work with. This enables them to refine their results. Furthermore, each company uses its own algorithms (formulas in which various kinds of information are assigned different weights) with which it processes the data at its disposal.

²⁹ <https://homedna.com/product/gps-origins>, click on “How accurate is the test?”

³⁰ <https://livingdna.com/legal/Living-DNA-terms-of-service>, Part 3. 1.

³¹ <https://www.myheritage.com/terms-and-conditions>.

³² <https://blogs.ancestry.com/cm/ancestry-tourism-traveling-to-your-familys-past/>.

³³ See Airbnb press release at https://news.airbnb.com/heritage-travel-on-the-rise/?utm_source=Airbnb.

³⁴ See <https://blog.myheritage.com/2017/06/introducing-our-new-dna-ethnicity-analysis/>.

Because of these variations, the information resulting from an ancestry test may not be 100 percent accurate, is likely to differ from company to company, and may even change over time.³⁵ It's best to think of these tests as providing general indications of where your ancestors came from.

Finding People Related to You

It's exciting to think that you may discover a long-lost relative through a DTC genetic test. MyHeritage devotes a whole section of its website to such stories.³⁶ Some companies' television commercials also focus on how the tests can help to find people related to you:

<https://www.ispot.tv/ad/wCUQ/23andme-dna-kit-100-percent-family>

<https://www.ispot.tv/ad/Aftj/ancestry-dna-tnt-teresas-story>

<https://www.ispot.tv/ad/wf9X/myheritage-dna-sisters-reunited-august>

These claims are not necessarily false, but they may not be true for everyone. As Catherine Nash, an academic geographer based in London points out, one of the problems with using these tests for genealogical purposes is the selectiveness of the DTC genetic testing company's database:

It only contains the people who have bought the tests and allowed their results to be entered. This is thus in no way a representative sample of the people who could possibly match another individual. The information to be gleaned from the details of other matching customers is entirely dependent on the sort and number of customers who have contributed to the database. (This is also the case in genetic surname studies.) A larger and more diverse set of participating customers would produce a different list of matches and their self-identified ethnic or geographical origins.³⁷

In other words, the only matches you will get are other people who are also customers of the same DTC genetic testing company. It is possible that a match with another customer may lead to one that is not in that company's database; for instance in the MyHeritage ad, a woman's son takes the test and discovers his mother's sister, who presumably took a test with the same company. The sisters are happily reunited as a result. You may also be able to identify relatives you didn't realize you had through a family tree on the company's site. That will show not only other customers that the company predicts are related to you but people those customers have

³⁵ See Brian Resnick, "The limits of ancestry DNA tests, explained," Vox (updated May 29, 2019), available at <https://www.vox.com/science-and-health/2019/1/28/18194560/ancestry-dna-23-me-myheritage-science-explainer>. See also Anjali Patil, "Did your Ancestry.com DNA results change dramatically? Here's why" CBC News (September 17, 2018), available at <https://www.cbc.ca/news/canada/nova-scotia/ancestry-genealogy-website-dna-result-changes-1.4826831>.

³⁶ See <https://stories.myheritage.com/>.

³⁷ "Genetic genealogy: 10 reasons to be wary" (reprinted in 2016 from the original 2006 article for *L'Observatoire de al Génétique*), available at <https://catherinenash.website/2016/02/26/genetic-genealogy-10-reasons-to-be-wary/>.

added to the family tree to fill in the blanks, even though those people didn't take the test and may have died long ago.

I didn't discover a long-lost sister, but I wondered if my brother was actually adopted when he failed to show up in my matches on 23andMe, since I knew he had taken the company's ancestry test. It turned out that he had not opted-in to allow others to see that they may have a genetic connection to him. Once he did, he appeared in my matches at 51.56 percent shared DNA.

After my brother, the next closest possible relative of mine who opted to be shown to me from the 23andMe database was a first cousin, once removed (which would be the child of one of my first cousins). I didn't recognize this person, though she may be related, but I did recognize the name of another first cousin, once removed, and I know he is from my father's side of the family – something that 23andMe didn't know, because it does not appear to have any information about my father, his siblings, or his parents. I could add that information to my family tree on the site, and I could also confirm, as the company asks me to do, that the matches I'm shown are correct. Any information I provide would give the company more data to use. But if I put the wrong information in my family tree or confirm a match is correct when it isn't, it could skew the accuracy of the company's DNA matches.

I received an email from the MyHeritage "Tree Consistency Checker" asking if I could clear up some issues with my family tree there: the maiden name of someone's wife is the same as the husband's, and the birthplace of someone else has two different spellings. I didn't provide that information originally, but I could apparently help fix it if I thought I knew the correct answers.

None of my top ten DNA matches on MyHeritage, based on the strength of the relationship, is among any of my matches on 23andMe. I presume that's because they didn't take the 23andMe test. And while none of my DNA matches on MyHeritage are close relatives, there are close relatives in my family tree. Most of them were not put there by me, so they must have come from others. None of my matches appear in my family tree, however, and if I want to see other people's family trees to try to understand the connection to mine, I'd have to upgrade to another program that would cost \$120 per year. Alternatively, I could ask them directly about their families if they agreed to be contacted.

I recognized a match on Ancestry, whose relationship to me is described as a first to second cousin. She is, in fact, a first cousin. I can see some of her family tree for free; to see more I have to pay to upgrade. A person who is described as a second cousin on 23andMe is shown on Ancestry as a third to fourth cousin. The range for estimated matches grows wider as relationships are more distant – for instance, in my MyHeritage matches, one person is described as being anywhere from a first cousin, twice removed to a fourth cousin, and another as a second to a fifth cousin.

My matches on LivingDNA were even more distant, and there is no family tree feature; that is apparently coming in 2021.

HomeDNA does not provide DNA matches or family trees; its focus is on identifying the geographic regions from where your genes originated and the migration routes they followed.

As with information about one’s origins, it’s important to understand that the DNA matches DTC genetic testing companies provide are *estimates* based on comparing your data to those of other customers and any additional information that you and other customers have supplied. As 23andMe explains, “The relationship 23andMe presents is the most likely relationship, based on not only the amount of DNA, but also the pattern of DNA segments, your self-reported ages, and your relationships to other relatives you both have in common. But there is great diversity in the amount of DNA shared between any two individuals with a particular relationship.”³⁸ In its terms of service, LivingDNA notes that another reason why matches may not necessarily be reliable is that it cannot verify the identity of the person taking the test:

“If you participate in Family Networks you should view ‘matches’ as potential relatives only and any indications we provide of how closely or distantly related a ‘match’ may be, including where this is presented in the form of a family tree, as an estimate only. The reliability of the estimate will vary. This is, in part, due to the limitations of the process, but also because Living DNA is not able to verify the identity of any person who provides a sample for testing or who uploads their data. The availability and accuracy of non genetic data within our database, such as birth dates, will also impact on the accuracy of the potential family trees provided.”³⁹

Since the matches that result from DTC genetic tests and how they are described vary from company to company and may not be completely accurate, consumers may need to pay for expanded ancestry services that some companies provide and do a lot more sleuthing on their own to get a fuller picture of their families.

Gaining Insights into Your Health and Wellness

All of the DTC genetic testing companies we studied offer health-related services. Some provide traits or general wellness reports indicating how likely it is that you’ll have certain characteristics such as snoring, freckles, or red hair, others show how particular diets and exercises could help you lead a healthier life. These may be included in the basic ancestry packages or available separately.⁴⁰ Some companies also offer tests to indicate your risks for certain health conditions. These advertisements from 23andMe illustrate the range of health-related services it offers:

<https://www.ispot.tv/ad/7qoF/23andme>

<https://www.ispot.tv/ad/ZpU9/23andme-health-happens-now>

<https://www.ispot.tv/ad/opG5/23andme-meet-your-genes>

³⁸ See <https://you.23andme.com/tools/relatives/faq/>, What relationships are predicted by 23andMe?

³⁹ <https://livingdna.com/legal/Living-DNA-terms-of-service>, part 4.1.

⁴⁰ Of the DTC genetic tests we purchased, only 23andMe included traits information in the basic ancestry package.

Each ad has a disclaimer that is commensurate with the type of health information the tests produce. For instance, the first ad is primarily about the traits and wellness information the company offers and makes this general disclaimer:

“Results will vary due to differences in each individual’s DNA. On average, users receive at least one or two results that may help with proactively managing health.”

The second ad is focused on the health predispositions that some tests may reveal and has this disclaimer:

“23andMe reports do not diagnose disease or describe overall risks of developing disease. Tests selected variants only. Visit [23andMe.com/testinfo](https://23andme.com/testinfo) for important test information.”

In the third ad, which is even more specific about the kinds of health risks that some tests may indicate, the disclaimer says:

“23andMe tests for selected genetic variants only and cannot diagnose or describe overall risk of developing any type of cancer or disease. Our Type 2 Diabetes health predisposition report does not describe the overall likelihood of developing type 2 diabetes. Each test is most relevant for certain ethnicities. Visit [23andMe.com/testinfo](https://23andme.com/testinfo) for important test information.”

These disclaimers are in small, light gray type; we had to stop the commercials to read them.⁴¹

At the link⁴² provided in the second and third ads, 23andMe explains more about its health risk reports under Genetic Health Risks and emphasizes that the results “should **not** be used to make medical decisions.” It recommends that consumers consult with a healthcare professional to interpret the test results and encourages them to speak with a genetic counselor before and after being tested.⁴³

Ancestry offers traits information with its basic ancestry service as an add-on for \$20 (we did not purchase it). The company sells a separate service, AncestryHealth®, which is described on its website as being able to show “if you’re at normal or higher risk for conditions like inherited breast cancer, colon cancer, and heart issues.” The company makes this disclaimer: “The tests offered by AncestryHealth® are physician-ordered and are not diagnostic. The tests are not reviewed or approved by the FDA and are not available in NY, NJ, RI or GU.” Scroll down further and you’ll see that “physician-ordered” does not mean the tests are ordered by your doctor; you fill out a questionnaire which goes to the company’s “independent network of

⁴¹ In addition to television ads, some companies use other media to promote their tests, such as videos on YouTube. This example from 23andme, <https://www.youtube.com/watch?v=msBITuIygtw>, is a testimonial from a woman who credited the results of her test for warning her and other family members about their potential for developing cancer. As with the television ads, the disclaimers were easiest to read by stopping the video.

⁴² <https://23andme.com/testinfo/>.

⁴³ For a comparison of 23andMe’s services and what’s included in each see <https://www.23andme.com/compare-dna-tests/?nav1=true>.

doctors” to determine if you are eligible for the service. The company advises consumers to consult with their own healthcare providers before taking action on the basis of the health reports they receive, and also offers access to a network of independent board-certified physicians and genetic counselors with which it partners to help consumers understand their results.

FamilyTreeDNA does not include traits or wellness reports in its basic ancestry service. On its homepage, the company offers a health service, the Tovana Genome Report, which does not require you to send in another DNA sample if you are already a customer, but does entail a large additional fee. It provides “details on nearly one thousand health categories and conditions, medication effects, and health traits.” As with the Ancestry health report, you must first fill out a questionnaire that is reviewed by an independent doctor. The company makes this disclaimer: “The Tovana Health Genome Report is not a diagnostic product. Involvement of a healthcare provider or genetic counselor is always encouraged for diagnostic purposes.”⁴⁴ In my portal I noticed another health-related service that I could upgrade to, the Vitagene Health Report, which provides lifestyle information such as insights on diet and exercise.

HomeDNA offers several “health and beauty” services, which are separate from the basic ancestry service we purchased and includes tests for “Food and Pet Sensitivity,” “Healthy Weight,” and “Skin Sensitivity.” A “Paternity” test is also available. Clicking on each one provides more information. The overviews of the food and pet sensitivity and healthy weight tests make clear that they are “not intended to diagnose, treat, cure, or prevent any diseases.”⁴⁵ The description of the food and pet sensitivity service also notes that it is not an allergy test and that the “report is provided for educational and informational purposes only.”⁴⁶ You must click on the “Details” of the paternity test to see that it is not for New York residents, as the state does not allow paternity testing at home.⁴⁷ The company also offers health-related tests for dogs and cats, and a mixed-breed dog DNA test.

LivingDNA offers a “Wellbeing Kit” that is intended to help understand “the role genetics plays with your lifestyle choices and how you can optimise your wellbeing to improve the quality of your life by making adjustments to your diet and exercise.”⁴⁸ This is separate from the basic ancestry service we purchased.

MyHeritage does not provide traits or wellness reports in the basic ancestry package we purchased and does not list health tests on its homepage, but customers have an option to pay for a “health upgrade,” which does not require another DNA sample. It provides reports about risks for certain health conditions such as heart disease, breast cancer and Alzheimer’s disease. As with the health risk tests offered by other companies, an independent doctor reviews a questionnaire that you complete to determine if you are eligible. MyHeritage uses the same network as Ancestry to provide genetic counseling if it is advised.

⁴⁴ <https://www.familytreedna.com/tovana>.

⁴⁵ <https://homedna.com/product/homedna-healthy-weight>.

⁴⁶ <https://homedna.com/product/homedna-food-and-pet-sensitivity>.

⁴⁷ <https://homedna.com/product/homedna-paternity>.

⁴⁸ <https://livingdna.com/kit/wellbeing-kit>.

The traits report that I received from 23andMe was interesting, but not very useful. It correctly predicted my eye color, the flavor ice cream I favor, and, in the “weird and wonderful category,” my ability to match a musical pitch. There wasn’t anything particularly “actionable” in my results that I don’t already do, however. For instance, I know that I have fair skin and that the lighter one’s skin is, the more important it is to protect it from sun exposure, so I should wear sunscreen when I’m outside.

In addition to the ancestry and health-related reports DTC genetic testing companies produce, some allow consumers to download their results in raw data form. The NHL warns that it is “challenging” to interpret raw genotype data on your own and says:

Relatively often, test results include false positives, which means that the service indicates an increased risk of disease when your risk is not actually higher than that of the general population. False positives and other errors can cause stress and anxiety.⁴⁹

The NHL also notes that there is little regulation of third-party interpretation services and advises that your healthcare provider can help you understand your results and determine next steps.

In approving 23andMe’s genetic health risk (GHR) tests, the FDA pointed out that:

The GHR tests are intended to provide genetic risk information to consumers, but the tests cannot determine a person’s overall risk of developing a disease or condition. In addition to the presence of certain genetic variants, there are many factors that contribute to the development of a health condition, including environmental and lifestyle factors.⁵⁰

The FDA also noted that health risk tests could produce false positives or false negatives and should not be used for diagnosis or to inform treatment decisions. The health information DTC genetic testing services provide may be helpful, but it’s clear that you shouldn’t act on the basis of results indicating a risk of a specific health condition or disease without consulting with your own healthcare provider.

In 2019 the U.S. Secretary of Defense issued a memo⁵¹ to service members warning them not to use DTC genetic testing kits because, among other things, they are required to report to the military any medical information that affects their readiness, and the health results they receive are not necessarily accurate.

It is also important for consumers to know that, as with ancestry tests, the information they receive from health tests may change over time as the companies compile more data and scientific research provides new insights. As MyHeritage explains in regard to its health reports:

⁴⁹ <https://medlineplus.gov/genetics/understanding/dtcgenetictesting/dtcrawdata/>, What can raw data from a direct-to-consumer genetic test tell me?

⁵⁰ See FDA press release (April 6, 2017), available at <https://www.fda.gov/news-events/press-announcements/fda-allows-marketing-first-direct-consumer-tests-provide-genetic-risk-information-certain-conditions>.

⁵¹ Available at https://www.scribd.com/document/440727436/DOD-memo-on-DNA-testing#from_embed.

“In the future, the scientific community may show previous research to be incomplete or inaccurate and future scientific research may change the interpretation of your DNA Results. As scientific knowledge advances, our DNA Health Reports may change and reflect different results in the future. For example, we might change the set of variations that we consider as part of your genetic predisposition for a specific condition. In addition, we might assign different values or classes to those variations, so variants that are harmful now will be classified as benign in the future and change your DNA Health Report. As another example, we may change the estimated risk level for a certain disease. We may also add conditions or diseases after you receive your DNA Health Reports, beyond those conditions and diseases that were listed on the pre-purchase pages when you ordered the DNA Health Reports.”⁵²

Warnings about Unexpected Results are Hard to Find

In addition to claims and disclaimers, we looked for information the companies provide about the possibility that the results of genetic tests may be surprising, even upsetting, and how to handle those situations. For example, what if you discover that one of your parents is not biologically related to you? Or that you may have a predisposition to a serious health condition?

The terms of service on the 23andMe website lists the risks and considerations regarding the company’s services, including that the fact that consumers should not assume the results will be positive or welcome, and:

You may learn information about yourself that you do not anticipate. This information may evoke strong emotions and has the potential to alter your life and worldview. You may discover things about yourself that trouble you and that you may not have the ability to control or change (e.g., your father is not genetically your father, surprising facts related to your ancestry, or that someone with your genotype may have a higher than average chance of developing a specific condition or disease). These outcomes could have social, legal, or economic implications.⁵³

There is also a link on the bottom of the homepage for Family Considerations, which leads to an article, “What Unexpected Things May I Learn from 23andMe?”⁵⁴ It discusses the surprises that may occur in your health results or ancestry results and how these may affect your family and relationships. There is a link in it to another article about navigating unexpected relationships.⁵⁵

⁵² <https://www.myheritage.com/terms-and-conditions>.

⁵³ <https://www.23andme.com/about/tos/>, section 5.

⁵⁴ <https://customercare.23andme.com/hc/en-us/articles/202907980>.

⁵⁵ <https://you.23andme.com/public/unexpected-relationships>.

On Ancestry, this information appears in the terms of service:

Unexpected Results: When using our Services, you may discover unexpected facts about yourself, your family, or your health (e.g. you may discover an unknown genetic sibling or parent, surprising facts about your ethnicity, unanticipated genetic test results, or unexpected information in public records). Once discoveries are made, we can't undo them.⁵⁶

It does not provide advice about how to deal with those results. If you click on Support Center at the bottom of the homepage and search for “unexpected results,” you will find articles about unexpected ethnicity results and DNA matches. They explain how unexpected results may happen, and the article about unexpected DNA matches has links to resources for help such as the NPE (Not Parent Expected) Friends Fellowship.

We liked the prominent feature on the FamilyTreeDNA homepage, “Have questions? We have answers.” It provides a link to the most common questions in the company’s Learning Center.⁵⁷ It was disappointing that there was nothing there about unexpected results, nor did we find anything using the search function on that page. In the terms of service, however, there is a section on “Considerations Regarding FamilyTreeDNA Services,” which warns that there may be unanticipated results.⁵⁸ No advice is provided about how to deal with them.

We couldn’t find anything about unexpected results on the HomeDNA or LivingDNA websites.

The only information about unexpected results on the MyHeritage website was in the terms and conditions, which sternly warns in bold print:

“By using the DNA Services, you acknowledge that you may learn information you do not anticipate from the DNA Results and from the DNA Reports, which may evoke strong emotions and has the potential to alter your life and worldview. You may discover things about yourself that trouble you and that you may not have the ability to control or change (e.g., your father is not genetically your father, or your ethnicity is not what you thought it is, or surprising facts related to your ancestry), or that you have a higher than average risk of developing an incurable condition like Alzheimer’s disease). Once you obtain this information, the knowledge is irrevocable. You should not assume that any information we may be able to provide to you, whether now or as genetic research advances, will be welcome or positive. These outcomes could have social, legal, or economic implications.

You further acknowledge that your use of the DNA Services and receipt of the resulting DNA Reports may have serious implications not only for you, but also for your immediate or other family members, since they share some

⁵⁶ <https://www.ancestry.com/cs/legal/termsandconditions>, section 1.3.

⁵⁷ <https://learn.familytreedna.com/faq/>

⁵⁸ <https://www.familytreedna.com/legal/terms-of-service>, section 5.

of your DNA. If you are in any way concerned about any such potential implications, DO NOT USE the DNA Services.”⁵⁹

If this information is so important for consumers to know that it is bolded, it shouldn't *only* be provided in the terms of service, where few people are likely to see it.

We were also concerned to find information in Ancestry's terms of service about how having bone marrow or stem cell transplants could result in unexpected tests results:

“Note to Users who have received a bone marrow or stem cell transplant: The purpose of the DNA Services is to provide genetic and genealogy results and related reports for your informational, recreational, educational and research use. If you have received a bone marrow or stem cell transplant, your AncestryDNA test may provide unexpected results because your saliva may contain cells with your DNA as well as cells with your donor's DNA. DNA for the test is extracted from the cells, and the combination of DNA sources can result in a failed test or a test that provides results based on your donor's DNA. Therefore, we recommend that those who have received a bone marrow or stem cell transplant do not take the AncestryDNA® test. If you have already taken the test, please contact us for further assistance.”⁶⁰

This is not something that consumers may think about before buying genetic test kits, and it seems to us that important information such as this should be more prominently disclosed.

Access to Historical Records Isn't Included in Basic Ancestry Services

Some ads for DTC genetic testing imply that you will learn information about your relatives such as where they lived, their occupations, and other details you might not know. These ads from Ancestry, for instance, highlight the wonderful things you could discover about what your ancestors did in military service or in the fight for women's rights:

<https://www.ispot.tv/ad/n6jc/ancestry-greer-wwii>

<https://www.ispot.tv/ad/n6jy/ancestry-wwii-untold-stories>

<https://www.ispot.tv/ad/nHlc/ancestry-generations-of-women>

The basic Ancestry service we purchased does not include access to historical records, however. You may be able to get some information from content that other customers post, but there is no guarantee that it is accurate, and in order to gain access to official birth and death records, census records, military records, newspaper stories and other historical archives through Ancestry and its related companies you need to subscribe to one of its records services at a monthly cost of \$24.99 to \$49.99 (there is also a 6-month option at a slightly reduced rate).⁶¹

⁵⁹ <https://www.myheritage.com/terms-and-conditions>, DNA Samples and DNA Results; DNA Reports.

⁶⁰ <https://www.ancestry.com/cs/legal/termsandconditions>, section 1.4.

⁶¹ <https://www.ancestry.com/cs/offers/subscribe>

23andMe, FamilyTreeDNA, LivingDNA and HomeDNA do not advertise or offer access to historical records.

MyHeritage has several ads, such as the one below, that include images of historical documents:

<https://www.ispot.tv/ad/AZIV/myheritage-instant-discoveries>

The company’s homepage features dozens of vintage photographs of individuals and families. Historical records are not included in the service we purchased, however. I discovered that when I signed into my MyHeritage account and saw a notice that there was a record of one of my relatives in the 1930 census. Clicking on it did not bring me to the census record, but to a page that offered two subscription options for access to historical records. There is a link on the company’s homepage for a price list, which provides a comparison of the subscription plans the company offers, what they include, and what they cost.⁶² (The basic DNA testing kit we purchased, which is not a subscription plan, appears at the bottom of that page and also when you click on “Order DNA kits” on the company’s homepage.)

Consumers may assume that access to historical records is part of the basic package for DNA ancestry tests, especially when that type of information is featured in commercials. There may be photographs and historical documents that other customers have posted on the sites, but they are not provided by the companies themselves. It’s important to look carefully at the service packages offered on DTC genetic testing companies’ websites to understand what they include. If you purchase access to historical records, be aware that you will be presented with a list of records that *may* pertain to your ancestors; you’ll need to sort through them to try to determine which do.

Free Trial Offers Don’t Always Make the Terms Clear Upfront

I noticed that there is a link on the MyHeritage homepage for “Historical records.” Clicking on it led to a form where you fill in the name of a person, and the date and place of birth if you have that information, to see what records may be available.⁶³ Anyone can do this, you don’t need to already be a customer, and I was not signed into my account at the time. I put in my husband’s information and was shown a list of records, some of which appeared to relate to him. Clicking on “view record” resulted in a pop-up for a free trial offer for access to historical records. It didn’t specify which of the company’s record access services the free trial was for or how much it would cost after it ended, but it did say that by filling in my name and email address I was accepting the “Service Terms.” Clicking on the link to those terms, I still didn’t see the service or cost information.

Since I wanted to know if the information would appear in the next step, and I did not want the fact that I was already a MyHeritage customer to affect what I might see, I made up a name and email address and clicked on “Continue.” That brought me to the enrollment form, which said that after 14 days I’d be charged \$10.15 per month (a 32 percent discount) and that I could

⁶² <https://www.myheritage.com/pricing>.

⁶³ <https://www.myheritage.com/research>.

cancel anytime, and asked for my payment information. It still didn't specify which records service I would be trying out or when I would have to notify the company that I wanted to cancel to avoid being charged. The cancellation details do appear, however, far down in the "Service Terms." They state that you will not be charged if you cancel anytime within the free trial period from the "My Purchases" page.⁶⁴ Perhaps the reference to "My Purchases" should have been a clue, but I didn't realize until later that I had opened an account for the fictitious person, even though I never actually enrolled in the free trial, simply by initially providing a name and email address. Though there is a function to delete your account, it didn't work because it required a password, which I hadn't created.

There were no free trial offers on the Ancestry website, but as an existing customer I received an email from the company inviting me to enroll in a free trial for access to historical records. The message didn't specify which access option the free trial was for or what the cost would be when it ended, but when I clicked on "Start free trial" in the email, it brought me to a page that showed the monthly and 6-month subscription options, what they include, and how much they cost. The lowest-cost option was pre-checked, but I could choose another one instead. There was an explanation on that page that I would be charged unless I canceled at least two days before the free trial ended. Once you make the choice of which option you want, you are taken to the enrollment page to provide your payment information.

We didn't see free trial offers on the other DTC genetic testing companies' websites, and I have not received emails from them in that regard. It probably wouldn't make sense for companies to offer free trials for ancestry or health tests, since the results can't be taken away from people once they have them, though access to their portals could be cut off. For consumers who are interested in ancillary services such as access to historical records, a free trial might be useful, but it is important for companies to tell them 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. We'd like to see that information provided *before* the enrollment page, as Ancestry did. Furthermore, no personal information should be collected prior to filling out the enrollment form for a free trial.

Up-selling is a Common Feature of DTC Genetic Testing Services

Once you become a customer, you're likely to receive offers from the company. These solicitations come in a variety of forms. When you log into your account to look at your test results, you may see invitations to upgrade your service or buy other products or services, such as more extensive information about your origins, expanded matching services, health-related reports, access to historical records, and personalized books that provide the graphs, maps, family trees, and other information you see online in glossy print form.⁶⁵ As an existing customer, these may be offered to you at discounted prices.

⁶⁴ <https://www.myheritage.com/terms-and-conditions>, Fees and Payments.

⁶⁵ I don't see ads in when I log into my account on HomeDNA, however.

Emails are another way that DTC genetic testing companies solicit customers to make additional purchases. I frequently receive marketing emails from most of the companies whose tests I purchased; even emails notifying me about new matches to my DNA may encourage me to buy other products and services for myself or to give DNA tests as gifts. U.S. law allows companies to send consumers marketing emails even if they didn't agree in advance to receive them, but the messages must include "clear and conspicuous" notice of the ability to opt-out.⁶⁶ All of the marketing emails I receive have an "unsubscribe" link or something similar. Some of the companies also provide controls for marketing emails in my account settings, others do not.

HomeDNA's privacy policy says: "We will periodically send you free newsletters and e-mails that directly promote the use of our website or services and may contain advertisements for third party companies or our Affiliates."⁶⁷ There are no settings to control marketing emails in my account, but I haven't received *any* promotional emails from the company. On its homepage, there is a place where anyone, customer or not, can sign up to get information about specials, news and product updates. I did not do that. There are no controls for marketing via the website.

Since LivingDNA is based in Europe, its privacy policy conforms to the General Data Protection Regulation under European law, which is very privacy-protective. The policy clearly states that the company will only send marketing communications if you opt-in to receive them, which I did through my account settings. I can easily change it to stop receiving them.⁶⁸ There are no controls for marketing via the website.

FamilyTreeDNA sends me marketing emails which state that I'm receiving them because I opted in at the company's website. Since I did not specifically do so, I assume that refers to the fact that I was required to agree to the company's terms of service and "privacy statement" in order to set up my account. The privacy statement says: "**Marketing Communications:** By creating an account, you are agreeing that we may send you promotional emails about our Services."⁶⁹ There is nothing in my account settings that enables me to stop them. In "Notification Preference" I can change whether I want to be notified of matches; I would think that I'd be able to manage marketing emails there as well, but apparently I must go through the unsubscribe process. There are no controls for marketing via the website.

As with FamilyTreeDNA, I had to agree to the MyHeritage Privacy Policy, which says under "How Do We Use Your Personal Information?" that it will use my personal information to market its product and services to me.⁷⁰ There are no controls for email solicitations in my account settings, or for marketing via the website, but there are controls for cookies under "My privacy."

⁶⁶ Can Spam Act of 2003: Core Legal Requirements, Cornell Law School Legal Information Institute, available at https://www.law.cornell.edu/wex/inbox/can-spam_act_core_requirements.

⁶⁷ <https://homedna.com/privacy>, section 5.1.

⁶⁸ <https://livingdna.com/legal/Privacy-Policy>.

⁶⁹ <https://www.familytreedna.com/legal/privacy-statement>, section 7 B.

⁷⁰ <https://www.myheritage.com/privacy-policy>, How Do We Use Your Personal Information?

Ancestry’s privacy statement says: “We use some Personal Information to market products and offers from us or our business partners. This includes advertising personalized to you based on your interests.”⁷¹ It was my choice whether to receive marketing emails, however. There is a very clear set of options in my account under “Email Settings.” They were not pre-checked; I opted in to receiving emails with promotional offers and personalized offers, and it’s easy to change those settings. There are no controls for marketing via the website.

The privacy statement on the 23andMe website said that by creating an account I agreed that the company may send me product and promotional emails.⁷² But as with Ancestry, the settings for email notifications under my “Preferences” were not pre-checked; I opted in to receive marketing emails, and I can easily change the setting if I want to stop them. There are no settings to control marketing via the website.

MyHeritage went the extra mile to try to sell me an upgrade – I received a call from a pleasant salesperson offering a steep discount on the company’s premium package, which includes access to historical records and other perks.⁷³ When I remarked on his British accent, he said he was actually calling from Israel. I thanked him for the information, but explained I was doing a research project and did not have the budget to make further purchases.

Customers are Encouraged to Participate in Research

Research can benefit individuals and society as a whole; for instance, by shedding new light on why certain people may be prone to developing specific health conditions or diseases. As 23andMe puts it on its homepage:

“When you opt in to participate in our research, you join forces with millions of other people contributing to science. Your participation could help lead to discoveries that may one day make an impact on your own health, the health of your family and ultimately, people around the world. (Look at you go.)”⁷⁴

In addition to health, research may be conducted for other scientific or historical purposes, such as anthropology and understanding human migration. It may also be used by groups of customers to explore similar interests.⁷⁵

But research can also benefit the companies by providing them with more data to work with and another revenue stream. As Ancestry explains in its privacy statement, “In some circumstances, a research partner or Ancestry may have a financial interest in the research arrangement.”⁷⁶

⁷¹ <https://www.ancestry.com/cs/legal/privacystatement#personal-info-use>.

⁷² <https://www.23andme.com/about/privacy/>, section 3. h.

⁷³ U.S. law also provides consumers with certain rights in regard to sales calls, *see* https://consumerfed.org/consumer_info/understanding-your-telemarketing-rights/.

⁷⁴ <https://www.23andme.com/>.

⁷⁵ *See* information about FamilyTreeDNA’s “Group Projects,” <https://www.familytreedna.com/legal/terms/group-project-participation>.

⁷⁶ <https://www.ancestry.com/cs/legal/privacystatement>, section 7.

None of the companies we studied force customers to agree to allow their genetic information to be used in research projects merely by using their services or accepting their terms and conditions (HomeDNA does not appear to engage in these types of research projects). Participation is strictly opt-in – that is, only if customers expressly agree to participate.

For instance, Ancestry’s explanation of its “Human Diversity Project”⁷⁷ makes clear that participation is completely voluntary and not required to use its products or services. It also notes that there are risks: customers’ data could be exposed as a result of a security breach; it might be possible for third-parties to identify individuals under certain circumstances from the aggregated data that is used in published research results; biological samples that are transferred to collaborators in research projects could be lost or stolen in transit; and the results of research provided to participants may be unexpected and “uncomfortable.”

Customers can withdraw from Ancestry’s research projects anytime, but the results that have already been processed will not be deleted, and if they want their DNA samples to be destroyed, that requires a separate request. There are similar provisions for the research conducted by other companies.

As with marketing for additional products and services, invitations to participate in research projects may be made in public sections of companies’ websites, in customers’ portals, and via email. DTC genetic testing customers should read the information about research projects carefully and consider the benefits and risks before agreeing to participate. It is also important for customers to understand that research is not always conducted strictly for altruistic purposes.

Does Marketing for DTC Genetic Testing Meet Truth-In-Advertising Requirements?

In its tips for sellers of DTC genetic testing services, the FTC says they should tell the truth about what their testing kits can do and disclose key information clearly and conspicuously.⁷⁸ As the FTC notes in its guidance for marketing DTC genetic tests, it’s not just false or misleading claims that can land companies in hot water – so can the omission of certain important information.

We did not find clear violations of truth-in-advertising requirements, but we did identify areas where we think that DTC genetic testing companies could make improvements to provide consumers with better information and adopt more consumer-friendly practices.

It is impossible for us, as it would be for any consumer, to assess the claims these companies make about the accuracy of the information derived from their tests. It is only by reading the details on the companies’ websites that you realize the results indicating where your DNA came from and to whom you may be related are *estimates* that may not be 100 percent accurate and

⁷⁷ <https://www.ancestry.com/dna/lp/informedconsent-v4-en>.

⁷⁸ Elisa Jillson, “Selling genetic testing kits? Read on.” Federal Trade Commission (March 21, 2019), available at <https://www.ftc.gov/news-events/blogs/business-blog/2019/03/selling-genetic-testing-kits-read>.

could change as the companies amass more data. While the frequently-asked questions and other educational information on companies' websites can help people better understand what they are getting and learn more about genetics in general, we wonder how many take the time to delve into them.

There are generally more caveats provided about health-related tests, perhaps because the stakes are higher. The disclaimers we saw in television ads and videos were fleeting and hard to read, however. Important advice such as consulting one's healthcare provider before acting on the results of such tests was fairly clear and prominent on the companies' websites.

Given the many factors that go into the results of ancestry and health-related tests, we believe that it would be best for DTC genetic testing companies to refrain from making specific claims about accuracy.

As we have noted, information about the potential for unexpected results and how to deal with them was hard to find, if it was provided at all. We think that this is useful for consumers to consider before they purchase genetic tests. This and other important information should not be provided only in the terms of service, which function mainly to provide legal cover for companies, not to bring important pre-purchase information to consumers' attention. Few people are likely to read or understand the terms of service, which are typically long and written in dense legalese.

We are also concerned that people may be led to think that access to historical records is included in the basic DNA testing packages, when in fact it costs extra. It is important to understand that you are not subscribing to a genealogy service that will trace your ancestors and provide details about their lives; what you receive are clues about yourself and your relatives, and it's up to you to do more work, and perhaps to pay more, to confirm and flesh out the information.

The basic facts about how DTC genetic testing works, and its limitations and consequences, should be prominently disclosed to consumers *before* they purchase the services and send in their swabs. It shouldn't be necessary to hunt for this information. It could be helpful for DTC genetic testing companies to place a prominent disclosure, "What You Should Know about Genetic Testing Services," on their homepages and on the test kits that provides key information:

- 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.⁷⁹

⁷⁹ 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 ethnicity, your relatives, or your health could be upsetting. We provide advice about how to deal with unexpected results.⁸⁰

The language of the disclosure should be tested to ensure that consumers understand it. Online disclosures could include links from words or phrases to more detailed information. For instance, in the last bullet point there could be a link from “advice” to information and resources that help consumers deal with unexpected results.

On packages in stores, QR codes or other technology could be used to enable consumers to see more information on their smart devices. Under no circumstances should basic information that consumers need *only* appear in the terms of service.

When offers to try a service for free are made, it's important to tell consumers exactly what the service includes, how much they will be charged if they continue after the trial period ends, and the deadline for canceling to avoid charges. In our view, this information should be provided *before* the enrollment page, and no personal information should be collected prior to filling out the enrollment form.

While there is currently no law in the U.S. that obliges companies to obtain consumers' opt-in consent to receive solicitations to buy additional products or services from them, or their partners, that is obviously the most consumer-friendly approach. We were disturbed by some terms of service that *require* consumers to agree to marketing and the fact that some companies do not provide customers with easy-to-use controls in their accounts to manage solicitations.

Privacy Is an Important Consideration Given the Sensitive Nature of Genetic Testing

The reasons for purchasing DTC genetic testing – the ability to gain insights into your origins and ethnicity, discover people who may be related to you and learn more about them, and identify personal traits and potential health risks – are also the reasons why privacy is such an important consideration in using these services. This information is obviously very sensitive, and if it is disclosed or used inappropriately, the results could be very harmful.

⁸⁰ Not all the DTC genetic testing companies we studied provided this type of advice; we encourage them to do so.

Companies may claim to “anonymize” personal information when sharing or using it for certain purposes – that is, strip it of anything that identifies particular individuals – but that doesn’t necessarily mean that the information can’t be re-identified or that it couldn’t be used to identify family members.⁸¹

As tedious as it is to read privacy policies, it is crucial for people who are interested in DTC genetic testing services to do so, ideally before purchasing the kits, but certainly before setting up their accounts. There are important things to consider about how the companies handle your personal information and about how you, as a customer, should handle it as well.

We examined the websites and privacy policies of the DTC genetic testing companies we studied to evaluate:

- Do the companies feature information about privacy prominently on their websites?
- Are the companies’ privacy policies clear and easy to read and understand?
- Is there data collection DTC genetic testing customers may not expect?
- Do the companies use or share customers’ genetic data for marketing?
- Under what circumstances are customers’ data shared with law enforcement?
- Are there other privacy issues customers should consider?
- Can customers delete their personal information?

In conducting this analysis, we noted how the companies’ practices align with some of the “Privacy Best Practices for Consumer Genetic Testing Services”⁸² developed by the Future of Privacy Forum (FPF) in 2018.⁸³ (We will refer to these as the FPF best practices.) Several DTC genetic testing companies pledged to follow these voluntary guidelines, including five of those we studied: 23andMe, Ancestry, FamilyTreeDNA, Living DNA, and MyHeritage. The FPF later removed FamilyTreeDNA from the list of supporting companies, however, when it was revealed that it was sharing customers’ personal information with the FBI in a manner that was not consistent with the best practices.⁸⁴

It’s important to acknowledge that while we can describe what the companies *say* they do in their privacy policies, we cannot assess what they *actually* do with customers’ personal information.

⁸¹ See Jamie Ducharme, “Millions of Americans Could Be Identified Using Consumer Genetic Databases—Even If They’ve Never Taken a DNA Test,” *Time* (December 13, 2018), available at <https://time.com/5423170/dna-test-identify-millions/>.

⁸² <https://fpf.org/2018/07/31/privacy-best-practices-for-consumer-genetic-testing-services/>.

⁸³ For information about the FPF go to <https://fpf.org/about/>.

⁸⁴ See Matthew Haag, “FamilyTreeDNA Admits to Sharing Genetic Data with F.B.I.” *New York Times* (February 4, 2019), available at <https://www.nytimes.com/2019/02/04/business/family-tree-dna-fbi.html>.

Do the Companies Feature Information About Privacy Prominently on Their Websites?

All of the companies we studied provide links to their privacy policies at the bottom of their websites. This has become standard business practice. As with the terms of service, however, it's doubtful that many consumers will click on the link and read the privacy policy. Therefore, it would be helpful for DTC genetic testing companies to bring information about privacy to consumers' attention more prominently. Some of companies we studied attempt to do this.

For instance, on 23andMe's homepage it says:

“Discovery should never come at the expense of privacy. Your data is encrypted, protected and under your control. You decide what you want to know and what you want to share.”⁸⁵

Clicking on Learn More there leads to the company's privacy policy.

FamilyTreeDNA's homepage features this statement:

“**We won't share your DNA.** We believe your DNA belongs to YOU and only you . . . period. For that reason, we will never sell your DNA to third parties. Can the other guys say that?”⁸⁶

There is a link from this to the company's privacy policy.

LivingDNA's homepage conspicuously states:

“With Living DNA you are always in charge of your DNA. We keep your DNA anonymous and safe, whilst making sure only you can tell us what you want us to do with it. We never share your DNA without your explicit request.”⁸⁷

Clicking on Read More there leads to the company's privacy policy.

Information about privacy is not as prominent on the other sites, however.

Clicking on the privacy link at the bottom of the Ancestry website leads to a clear statement about the importance of privacy and why consumers should trust the company with their personal information.⁸⁸ There is a link from there to the full privacy policy.

The homepage for HomeDNA has a prominent link to “Answers you can trust for important questions.” It is not clear from this heading, however, that some of the FAQs are about privacy.

There is nothing on the MyHeritage homepage about privacy except for the link at the bottom to the company's privacy policy.

⁸⁵ <https://www.23andme.com/>.

⁸⁶ <https://www.familytreedna.com/>.

⁸⁷ <https://livingdna.com/>.

⁸⁸ <https://www.ancestry.com/cs/privacyphilosophy>.

Are the Companies' Privacy Policies Clear and Easy to Read and Understand?

The FPF best practices call for companies to make their privacy policies easy to read and begin them with a high-level overview of key principles, particularly regarding how genetic data is collected, used and shared.

23andMe's privacy statement⁸⁹ is nicely set up and easy to read. It provides a high-level overview of the information, including genetic data, that the company collects about customers, how it is used, what access and controls customers' have, how the information is secured, and the risks and considerations connected with the information, such as the possibility of a data breach or unexpected test results. The full privacy statement that follows is well-organized. The table of contents has links embedded in the subject headings and subheadings, making it easy to jump to areas of particular interest. The first section provides definitions of key terms. Subsequent sections clearly explain how the company handles customers' data and the controls it provides in that regard.

Ancestry's privacy statement⁹⁰ starts with an overview in the form of FAQs. The full privacy statement begins with an explanation of recent changes and provides a table of contents with embedded links. It lacks a section that provides definitions of key terms, however, such as "personal information." This would be helpful. We liked the format Ancestry uses to lay out the information about its privacy practices, with headings on the left and details on the right in some sections. The text is clear and easy to read.

FamilyTreeDNA's privacy statement⁹¹ does not provide a high-level overview at the beginning, nor is there a table of contents, which we think would be very helpful. It also lacks a section of definitions, but it does define some terms such as "personal information" where they are used. It is relatively clear, though the formatting and language could be simpler to make it easier to read.

HomeDNA's privacy policy⁹² also lacks a high-level overview, table of contents, or definitions section. The information is presented in long, dense paragraphs and is interrupted in the middle by a lengthy explanation of how the company complies with the Privacy Shield (an agreement between the U.S. government and the European Commission regarding how Europeans' personal information will be handled if it is transferred to this country⁹³). The formatting and language of the privacy policy make it very difficult to read and we found parts of it confusing.

LivingDNA's privacy statement⁹⁴ starts with an introduction that provides some high-level information about its privacy practices and lists the subject areas to be discussed in more detail in the sections that follow, though there are no embedded links. It does not have a section for

⁸⁹ <https://www.23andme.com/about/privacy/>.

⁹⁰ <https://www.ancestry.com/cs/legal/privacystatement>.

⁹¹ <https://www.familytreedna.com/legal/privacy-statement>.

⁹² <https://homedna.com/privacy>.







⁹³ See <https://www.privacyshield.gov/welcome>; this agreement was recently struck down by a court in Europe and will need to be renegotiated.

⁹⁴ <https://livingdna.com/legal/Privacy-Policy>.

definitions, but it does explain what various terms mean as they are used. Since the company is based in Europe, the privacy policy provides background about the General Data Protection Regulation, the European privacy law, and reflects its requirements. Some of the terms that are used, such as “legitimate interest,” may not be familiar to consumers in the U.S. Nonetheless, the language is fairly easy to understand and the format is reader-friendly.

The MyHeritage privacy policy⁹⁵ begins with a high-level overview. The full privacy policy does not have a table of contents or definitions section, but important information such as what the “personal information” that is collected includes is clearly explained. It is fairly easy to understand, though the language and formatting could be improved to make the privacy policy easier to read.

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 |

Is There Data Collection DTC Genetic Testing Customers Might Not Expect?

Third-party trackers

People expect companies to collect information about them that is necessary to make transactions and create accounts, such as their names, addresses, phone numbers, email addresses, and payment details. In the case of DTC genetic testing services, customers also provide their saliva samples. Due to the nature of the ancestry and health-related services they provide, DTC genetic testing companies may ask customers for their dates of birth, sex, family

⁹⁵ <https://www.myheritage.com/privacy-policy>.

members, and health information. People may also expect companies to set cookies on their browsers to recognize them when they return to the websites.

They may not be aware, however, of third-party trackers that observe them when they visit DTC genetic testing companies' websites. These trackers are invisible but can be seen using tools such as the Ghostery⁹⁰ browser extension. Some of these tracking companies perform analytical work for websites – measuring the numbers of visitors, the pages they view, how long they spend there, and other aspects of site usage. Some are ad networks that follow people's computers or smartphones as they use them to visit various websites over a period of time. With this information the companies can build profiles of internet users and their interests, enabling them to help businesses “target” advertisements to likely customers. These companies may also connect websites that want to sell ad space to businesses that want to target ads to people who visit those sites. Some trackers perform a mix of functions.

Third-party trackers appeared on all of the DTC genetic testing companies' websites we studied, and are commonly found on other businesses' websites.

23andMe clearly explains the presence of these trackers in its privacy statement:

“We permit third party advertising networks and providers to collect Web-Behavior Information regarding the use of our Services to help us to deliver targeted online advertisements ("ads") to you. They use cookies and similar technologies, to gather information about your browser's or device's visits and usage patterns on our Services and on other websites over time, which helps to better personalize ads to match your interests, and to measure the effectiveness of ad campaigns.”⁹⁶

Ancestry is less clear about this in its privacy statement. In describing the information collected from customers through their use of its services, it refers to its cookie policy. There it explains that some cookies are set by Ancestry, others by third parties. In regard to the latter, it says:

“Third party Cookies: these Cookies do not belong to Ancestry. They are owned by other companies, like Google or YouTube, and are used for site analytics and advertising purposes. See further details below on how to manage these Cookies. Third-party Cookies will be providing a service to Ancestry or a function to us but Ancestry cannot control how those third-party Cookies are used.”⁹⁷

The point that the company cannot control how third-party cookies are used is important; we'd like to see this clearly disclosed in companies' privacy policies.

FamilyTreeDNA says that it, and its third-party “partners,” use cookies and other tracking technology to “identify you, personalize the Services and our offers to you, determine the success of marketing campaigns, provide security, evaluate Service usage, collect demographic

⁹⁶ <https://www.23andme.com/about/privacy/>, section 4.b.

⁹⁷ <https://www.ancestry.com/cs/legal/AboutCookies>.

information about users, and to deliver targeted advertising on our site and on other sites.”⁹⁸ It also refers to its cookie policy for more information. There it says:

“Third-party cookies are cookies that another party places on your browsing device via our websites. Third-party cookies provide a service or function to FamilyTreeDNA, but we cannot control how those third-party cookies are used.”⁹⁹

HomeDNA does not make the presence of third-party trackers clear in its privacy policy, except for acknowledging the use of Google Analytics. But with Ghostery one can see more than a dozen other trackers at any given time on the website, including companies involved in advertising. In explaining that it does not respond to browser-based “do not track” signals, the company says “We do not have any third parties that push content to our site.”¹⁰⁰ We are not sure what that means.

LivingDNA’s privacy policy states that it collects information about individuals from third parties such as analytics providers, advertising networks, and search information providers.¹⁰¹ It refers to its cookie policy, which describes the types of cookies that may be set, including third-party cookies which are used primarily for advertising and marketing purposes.¹⁰²

MyHeritage does not make the presence of trackers clear in its privacy policy. It refers to its cookie policy, which explains first-party and third-party cookies and says:

“Third-party cookies will generally be providing a service to MyHeritage, but we cannot control how those third-party cookies are used. You should check the third party’s website for more information on how they use cookies. In addition, please note that the parties that set third-party cookies can recognize your computer both when it visits our website and when it visits certain other websites or mobile applications.”¹⁰³

It’s important to point out that these trackers cannot see your test results, family tree, DNA matches or other content on the password-protected section of a DTC genetic testing company’s website. But they could observe that you went from a DTC genetic testing company’s site to a website about a particular country, or that you were on a page of a DTC genetic testing company’s site about a test it offers for a certain health risk and later visited a website about that health condition. Like pieces of a puzzle, bits of information such as these can be assembled to form a revealing picture of you.

⁹⁸ <https://www.familytreedna.com/legal/privacy-statement>, section 3.B.

⁹⁹ <https://www.familytreedna.com/legal/cookie-policy>, section 2.

¹⁰⁰ <https://homedna.com/privacy>, section 1.3.

¹⁰¹ <https://livingdna.com/legal/Privacy-Policy>, Part B.3.

¹⁰² <https://livingdna.com/legal/cookie-policy>.

¹⁰³ See link from privacy policy, <https://www.myheritage.com/privacy-policy>.

When companies permit third-party trackers, in return for payment, services or something else of value, to be on their websites to collect information about individuals' online behavior and use it for their own purposes, are they "selling" individuals' data to those trackers? We believe they are, at least according to the California Consumer Privacy Act (CCPA), which defines "sell" as:

(t) (1) "Sell," "selling," "sale," or "sold," means selling, renting, releasing, disclosing, disseminating, making available, transferring, or otherwise communicating orally, in writing, or by electronic or other means, a consumer's personal information by the business to another business or a third party for monetary or other valuable consideration.¹⁰⁴

Some may argue otherwise, or assert that these trackers are service providers rather than third parties, so the CCPA's requirement to provide individuals with easy means to opt of sale of their data to third parties does not apply. That is incorrect, in our view, when those trackers are using the data they collect about individuals' online behavior for their own purposes.

You can try to manage cookies, web beacons and other tracking technologies from third-party trackers yourself, but it can be time-consuming and difficult, and opting out of targeted marketing through advertising industry self-regulatory programs or using ad-blocking tools does not necessarily prevent information about your online behavior from being collected. Ghostery blocks most trackers by preventing them from communicating with your internet browser, and there are similar tools available in the market.

Using social media in connection with DTC genetic testing services

Another thing that customers may not realize is that their use of social media in connection with a DTC genetic testing service may allow personal information to be collected about them and other people. For instance, 23andMe says:

"Our Services include Social Media Features, such as the Facebook "Like" or "Share" button and widgets ("Features"). These Features may collect your IP address, which page you are visiting on our site, and may set a cookie to enable the Feature to function properly. They may also allow third party social media services to provide us information about you, including your name, email address, and other contact information. The information we receive is dependent upon your privacy settings with the third party social media service. Features are either hosted by a third party or hosted directly on our site. Your interactions with these Features are governed by the privacy statements of the third party companies providing them. You should always review and, if necessary, adjust your privacy

¹⁰⁴ See TITLE 1.81.5. California Consumer Privacy Act of 2018, section 1798.140(t) (1), available at http://leginfo.ca.gov/faces/codes_displayText.xhtml?division=3.&part=4.&lawCode=CIV&title=1.81.5.

settings on third party websites and services before linking or connecting them to our website or Service.”

It further warns:

“If you use a third party site, such as Facebook or Twitter, in connection with our Services to communicate with another person (e.g., to make or post referrals or to request that we communicate with another person), then in addition to that person's name and contact information, we may also collect other information (e.g., your profile picture, network, gender, username, user ID, age range, language, country, friends lists or followers) depending on your privacy settings on the third party site. We do not control the third party site's information practices, so please review the third party's privacy statement and your settings on the third party's site carefully.”¹⁰⁵

Ancestry's privacy statement says:

“If you interact with social media through the Services, for example “Share,” “Post,” “Tweet,” “Pin,” or “Follow Us” links to sites such as Facebook, Twitter, Pinterest, Instagram, and YouTube, Ancestry will collect these interactions and whatever account information these services make available to us. Your interactions with these features are governed by the privacy statement of the applicable third-party company.”¹⁰⁶

FamilyTreeDNA advises that if customers choose to disclose their personal information to family members and others outside of its services, including through third-party services such as social networks and third-party apps that connect to its website through application programming interfaces, those parties may use customers' personal information differently than it does. It does not say whether these interfaces enable it to obtain information about customers from those third-parties.¹⁰⁷

The MyHeritage privacy policy says:

“Third Party Account Authentication Services: You may link an account from Facebook or Google to your account on our Service, for authentication. This will allow you to use your credentials from the other service to create a MyHeritage account or to sign in to MyHeritage, without having to enter details manually such as your email address. If you choose to do so, we will collect and use the information you authorized to share with us via that service, (for example, the email address for a connected Facebook or Google account), in accordance with this Privacy Policy.”¹⁰⁸

¹⁰⁵ <https://www.23andme.com/about/privacy/>, section 2.a.

¹⁰⁶ <https://www.ancestry.com/cs/legal/privacystatement#usage-info-collect>, section 4.

¹⁰⁷ <https://www.familytreedna.com/legal/privacy-statement>, section 7.D.

¹⁰⁸ <https://www.myheritage.com/privacy-policy>, “What personal information is collected from or about you?”

23andMe provides similar information about signing in through third-party services.

Neither HomeDNA's nor LivingDNA's privacy policies say anything about collecting personal information from customers' use of social media.

It's important to review the privacy settings of your social media accounts and apps carefully before using them in connection with DTC genetic testing services to control the personal information that is shared by doing so.

Do DTC Genetic Testing Companies Use or Share Customers' Genetic Data For Marketing?

Businesses typically use the information they collect about customers to try to sell them additional goods and services, and they sometimes share customers' personal information with other companies in exchange for some form of compensation. As we noted earlier, there are few federal or state laws that restrict the disclosure or use of genetic information,¹⁰⁹ so DTC genetic testing companies are generally free to use and share it for marketing purposes. Because of the sensitive nature of genetic information, the FPF best practices call for DTC genetic testing companies to obtain customers' separate, express consent before sharing it with third parties¹¹⁰ or using it for their own marketing, with some exceptions.

For instance, under the FPF best practices it is not "marketing" when a company uses a customer's genetic information as a basis to make an offer to that person on its website, but it *is* marketing when the company makes the same offer to the person in some other way, such as by email or phone. Furthermore, the FPF best practices do not require separate express consent for companies to use customers' genetic data to market to them if it's done as a follow up to a traits or general wellness test and the intent to do so was described in the initial agreement for the service. These distinctions make it difficult to assess what the companies we studied, most of which pledged to follow the FPF best practices, mean when they refer to "marketing" in regard to their use of customers' genetic data. With this caveat, we describe what their privacy policies say about using and sharing customers' genetic data for marketing purposes.

In its privacy policy, 23andMe says:

"We and our third party service providers will not use your Sensitive Information, such as Genetic Information and Self-Reported Information, for targeted marketing without asking for and receiving your explicit consent."¹¹¹

¹⁰⁹ See Justin Brookman, Director, Privacy and Technology Policy, *Direct-to-Consumer Genetic Testing: The Law Must Protect Consumers' Genetic Privacy*, Consumer Reports (June 2020), available at <https://advocacy.consumerreports.org/wp-content/uploads/2020/07/DTC-Genetic-Testing-White-Paper-4.pdf>.

¹¹⁰ Service providers, such as outside labs that conduct DNA testing, are not considered "third parties."

¹¹¹ <https://www.23andme.com/about/privacy/>, section 4.b.

Ancestry says:

“Ancestry does not share your Genetic Information with third-party marketers, insurance companies, or employers, and we will not use your Genetic Information for marketing or personalized advertising without getting your explicit consent.”¹¹²

FamilyTreeDNA’s privacy policy is somewhat confusing in this regard. The personal information it says it collects includes genetic information,¹¹³ and it states that it uses customers’ personal information in its marketing,¹¹⁴ but in describing the primary purposes for which it uses genetic information, marketing is not mentioned.¹¹⁵ We are therefore unsure if it uses customers’ genetic information for its own marketing purposes. The privacy policy does clearly state that the company will not share genetic information with third-party marketers without customers’ express consent.¹¹⁶

HomeDNA’s policies in this regard are even more unclear. The only place in the privacy policy where genetic information is specifically mentioned is in the section about the Privacy Shield, which is intended for European customers. It includes genetic information in the description of “Sensitive Personal Data” and says for such data individuals will be given “the opportunity to affirmatively and explicitly consent (“opt-in”) to the disclosure of the information to a non-Agent third party or the use of the information for a purpose other than the purpose for which it was originally collected or subsequently authorized by the individual.” Does this apply to U.S. customers? We are not sure. Even if it does, this convoluted language, which is typical of the company’s privacy policy, makes this hard to understand.

LivingDNA’s privacy statement has a section about genetic data that explains its uses and the basis for them under European law. Those uses do not include marketing, and the company states:

“We use your genetic data to provide you with your [sic] the service/reports you order. What information we hold will depend on the reports you order from us. If you maintain an account with us, we will store your genetic data for you. We may use it to update your results (if applicable), and to provide further services which may require your data to be further analysed. We will seek your consent before processing this data to provide you with any other services other than to update your results.”¹¹⁷

¹¹² <https://www.ancestry.com/cs/legal/privacystatement#usage-info-collect>.

¹¹³ <https://www.familytreedna.com/legal/privacy-statement>, section 3.

¹¹⁴ *Id* section 4.A.

¹¹⁵ *Id* section 4.B.

¹¹⁶ *Id* section 5.

¹¹⁷ <https://livingdna.com/legal/Privacy-Policy>, Part A.

It does not appear that the company uses or shares customer’s genetic data with third parties for marketing purposes, though this could be made clearer. The company emphatically states that **“We do not sell customer data, ever.”**¹¹⁸

The MyHeritage privacy policy says that it will “never sell or license DNA information or health information to any third parties without your explicit informed consent.”¹¹⁹ We assume this means it does not share customers’ genetic data with third parties for any type of compensation, though this could be made clearer. It does not appear that the company uses customers’ genetic information for its own marketing, though this could be made clearer as well. In the section of the privacy policy about how the company uses customers’ information, it says it may use “your contact information as well as information about your use of the Service” for marketing; “use of the service” is described in the section about the information the company collects as page views, IP addresses and other information about customers’ interaction with its website, not the results of their genetic tests.

We believe that DTC genetic testing companies should make clear in their privacy policies what personal information, including genetic data, they use in their own efforts to sell their products or services, regardless of how that marketing is conducted, and what information about customers they share with other businesses for marketing purposes.

Using and Sharing Customers’ Genetic Data for Marketing

| | |
|---------------|---|
| 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.”

¹¹⁸ <https://livingdna.com/legal/Privacy-Policy>, Part C.

¹¹⁹ <https://www.myheritage.com/privacy-policy>, Will MyHeritage disclose any of your personal information with third parties?

Under What Circumstances are DTC Genetic Testing Customers' Data Shared with Law Enforcement?

Information from DTC genetic testing companies may be useful to law enforcement agencies in solving crimes, but as we have noted, the information may not be accurate. And the larger question is whether and under what circumstances law enforcement should have access to this sensitive information.¹²⁰ What does this matter if you have done nothing wrong? It is possible to be accused of a crime you didn't commit on the basis of a genetic test that you, or a family member, have taken.¹²¹ Furthermore, the U.S. constitution protects individuals from unreasonable searches and seizures. To protect that right, there must be a valid legal process for law enforcement to obtain individuals' genetic information.

The FPF best practices allow DTC genetic testing companies to share customers' genetic data with law enforcement without their express consent only when they are required to hand the information over by a valid legal process. We believe that companies should not share *any* personal information, not just genetic information, with law enforcement without a subpoena, court order, or other legal process, and for the most part the policies of the DTC genetic testing companies we studied do not differentiate between customers' genetic data and other personal information in regard to law enforcement access. The FPF best practices also call for the companies to attempt to notify consumers if they have released their personal information to law enforcement and to issue public "transparency reports" at least once a year describing the requests they have received from law enforcement for genetic data.

23andMe's privacy statement says that it may be required to disclose customers' personal information in response to lawful requests by public authorities, including to meet national security or law enforcement requirements.¹²² There is a link to the company's transparency report, which is updated on a quarterly basis. It shows the number of government requests the company has received for customers' data, the number of customers or accounts specified in those requests, and the number of times it has produced data in response to those requests "without the customer's prior, explicit consent," which is zero.¹²³ This begs the question: Were there instances in which customers were asked, and consented, to allow law enforcement access to the personal information 23andMe held?

Ancestry's privacy statement says it does not allow law enforcement agencies to use its services to investigate crimes or to identify human remains. To obtain any customer data, they must follow a valid legal process, and if Ancestry is compelled to provide it, the company promises to give customers advance notice, unless it is prohibited by law from doing so. We're not sure if the

¹²⁰ See Heather Murphy, "What You're Unwrapping When You Get a DNA Test for Christmas – To what extent is giving a DNA test also a present for law enforcement?" The New York Times (December 22, 2019), available at <https://www.nytimes.com/2019/12/22/science/dna-testing-kit-present.html>.

¹²¹ See William Brangham, Nsikan Akpan, Rhana Natour, "A father took an at-home DNA test. His son was then accused of murder." PBS NewsHour (November 2019), available at <https://www.pbs.org/newshour/show/a-father-took-an-at-home-dna-test-his-son-was-falsely-accused-of-murder>.

¹²² <https://www.23andme.com/about/privacy/>, section 4.e.

¹²³ <https://www.23andme.com/transparency-report/>.

company would ask customers for consent to provide their data to law enforcement; the privacy policy states that it does not “voluntarily cooperate with law enforcement.”¹²⁴

The privacy policy provides a link to Ancestry’s transparency reports.¹²⁵ There the company states that because of the sensitive nature of genetic data, it will insist on a court order or search warrant before even considering a request for that information. The annual reports, which are more detailed than 23andMe’s, show that the company has provided some customer data to law enforcement agencies involving criminal investigations for credit card misuse, fraud, and/or identity theft, pursuant to a valid legal process. In the 2015 report, the company acknowledges having provided DNA information in 2014 in response to a search warrant, but it does not appear to have provided genetic information to law enforcement since then.

As we noted before, FamilyTreeDNA was removed from the list of companies that support the FPF best practices because its policies regarding sharing information do not comply with them. Its privacy statement says:

“We may use the information you have provided to us in order to comply with the law and requests from government bodies. This means that we may provide information that we collect from you if that information is relevant to a court subpoena or to a law enforcement authority or other government investigation, provided this is permissible under applicable data protection law.”¹²⁶

This suggests that customers’ information may be available for law enforcement investigations without requiring a formal legal process. In fact, the company has set up a system, as explained in the privacy statement, to create “limited access law enforcement accounts (“LE Accounts”) which are permitted to upload genetic information to the database to identify the remains of a deceased individual or to identify the perpetrator of a homicide or sexual assault,”¹²⁷ as long as the agencies comply with its Law Enforcement Guidelines. According to those guidelines, legal process is required for any *additional* personal or genetic information: “FamilyTreeDNA requires a valid legal process in order to consider producing any additional information about our users not stated in our Terms of Service and Privacy Statement.”¹²⁸ The company states that it is working on an updated report containing the details of law enforcement requests; we did not see a link to any current or past reports.

The only thing that HomeDNA says in its privacy policy about sharing customers’ data with law enforcement is that it may have to disclose that information to “comply with relevant laws or to respond to subpoenas or warrants” served on the company. It does not make clear that a valid legal process is the only way it will provide this information, and there is no mention of or link to transparency reports.

¹²⁴ <https://www.ancestry.com/cs/legal/privacystatement#shared-info>.

¹²⁵ <https://www.ancestry.com/cs/transparency>.

¹²⁶ <https://www.familytreedna.com/legal/privacy-statement>, 5.D.

¹²⁷ *Id* section 5.E.

¹²⁸ <https://www.familytreedna.com/legal/law-enforcement-guide>.

LivingDNA’s privacy policy says:

“There are circumstances in which we may be legally required to disclose information. Examples of this include where we are subject to a binding court order, subpoena, or a legally binding direction by a regulator, and where we are required to share information with HM Revenue and Customs. We reserve the right to share personal information where we reasonably believe that we are legally required to do so. **We will not share your personal information with law enforcement agencies unless we believe that we are legally compelled to do so.**”¹²⁹

We did not see a link to transparency reports in the privacy policy.

In its privacy policy, MyHeritage says:

“We will not provide information to law enforcement unless required by a valid court order or subpoena for genetic information.”¹³⁰

We did not see a link in the privacy policy to transparency reports.

Since none of the privacy policies say that the companies will share customers’ data with law enforcement with their consent, in lieu of a valid legal process that obliges them to provide the information, we are not sure if they do. There is nothing to prevent customers from voluntarily allowing law enforcement agencies to access their data, but doing so might disclose information about family members as well.

We recommend seeking legal advice if you are asked to provide any information from genetic testing to law enforcement or if a DTC genetic testing company notifies you that there has been such a request.

Sharing Customers’ Personal Information with Law Enforcement

| | |
|---------------|--|
| 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 |

¹²⁹ <https://livingdna.com/legal/Privacy-Policy>, Part C.3.

¹³⁰ <https://www.myheritage.com/privacy-policy>.

Are There Other Privacy Issues DTC Genetic Testing Customers Should Consider?

Security

All of the companies claim they have implemented strong measures to prevent unauthorized access or disclosure of customers' information, ensure that it is used appropriately, and safeguard it. Given the sensitive nature of the data they collect and the fact that it includes not only customers' personal information but information about their families, security is very important. One thing to look for is what companies say about "encrypting" customers' data. Since even with the best security efforts there is always the possibility of a data breach, encryption – turning the information into a code that can only be read by someone who has a "key" to it – helps protect customers' personal information if it falls into the wrong hands.

Use of Encryption

| | |
|---------------|---|
| 23andMe | Encrypts "sensitive" customer data at rest and in transit |
| Ancestry | Encrypts customers' "personal information," nothing more specific |
| FamilyTreeDNA | Encrypts customers' financial data as it is transmitted for payment |
| HomeDNA | No reference to encryption |
| LivingDNA | Uses encryption, nothing more specific |
| MyHeritage | No reference to encryption |

It is possible that the companies use encryption, or use it more extensively than we can glean from what they say in their privacy policies. DTC genetic testing service customers are not in a position, nor are we, to assess the companies' security measures. Federal and states laws should require all companies to adequately secure the personal information they hold about individuals, to regularly test and update their security systems, and to certify at the highest level of corporate governance that they have done so.

Customers' Own Sharing of Personal Information

DTC genetic testing companies provide customers with controls over whether their DNA matches can view information about them, and in some cases what level of information they can see. For instance, your matches may not be able to see your family tree, or they may have a limited view of it. There are also options for how people with DNA matches can communicate with each other. It is important to pay attention to these controls when setting up an account.

It is also important for DTC genetic testing customers to consider who may have access to documents, photographs, videos and other content they upload to the companies' websites, what information they provide in surveys and online forums on the sites, and

how to respond to companies' requests for additional personal information. "User content" and "self-reported" information may be used by the companies to improve their products and services and for marketing. It may also be available for other customers to see.

In regard to comments on its blogs and on its forums, 23andMe advises:

"Please note that whenever you post something publicly, it may sometimes be impossible to remove all instances of the posted information, for example, if someone has taken a screenshot of your posting. Please exercise caution before choosing to share Personal Information publicly on our blogs, Forums or in any other posting."¹³¹

Another good piece of advice from 23andMe is:

"Before you disclose information about a family member, you should make sure you have permission from the family member to do so."¹³²

Location data is also a consideration. When DTC genetic testing customers use apps to access their accounts, their locations may be identified. There are other ways the companies may collect information about their locations as well; for instance, Ancestry has a program in which customers volunteer to find and photograph people's graves. In its privacy statement it notes:

"If you choose to be a photo volunteer for Find a Grave®, you provide your location to us which you can change or remove at any time."¹³³

Customers of DTC genetic testing services can download their results and upload them to other websites – for instance, to find additional relatives. But this raises a host of privacy and security concerns, including about access by law enforcement.¹³⁴ It's not just your own data – putting the results of your children's DTC genetic test out there can also put them at risk.¹³⁵ It is crucial to read the privacy policies of other websites before transmitting personal data to them.

Because the U.S. does not have a comprehensive data protection law and there are few state privacy laws, it is up to individuals to try to protect their privacy by limiting the

¹³¹ <https://www.23andme.com/about/privacy/>, section 2.

¹³² *Id.*

¹³³ <https://www.ancestry.com/cs/legal/privacystatement#security>.

¹³⁴ See Nila Bala, "We're Entering a New Phase in Law Enforcement's Use of Consumer Genetic Data," Slate (December 19, 2019), available at <https://slate.com/technology/2019/12/gedmatch-verogen-genetic-genealogy-law-enforcement.html>.

¹³⁵ See Nila Bala, "Why Are You Publicly Sharing Your Child's DNA Information?" The New York Times (January 2, 2020), available at <https://www.nytimes.com/2020/01/02/opinion/dna-test-privacy-children.html?action=click&module=Opinion&pgtype=Homepage>.

personal information they provide and using the controls that may be available from the companies with which they interact and from other sources.

California residents have specific privacy rights under the CCPA, including the right to know what personal information is collected and with whom it is shared, to opt-out of the “sale” of their personal information, and to access, correct, and delete their data.

23andMe provides a link in its privacy statement to a special notice for Californians,¹³⁶ but there is no link on the homepage to information about the CCPA. Californians should not have to wade through the privacy policy to find this information.

Ancestry’s privacy statement provides information about customers’ rights under the CCPA.¹³⁷ There is also a link on the homepage labeled “CCPA Notice at Collection,” though we don’t think that description clearly conveys that it is about Californian’s privacy rights.

We did not find anything about the CCPA in FamilyTreeDNA’s or LivingDNA’s privacy policies or on their homepages.

The MyHeritage privacy policy provides information about the CCPA¹³⁸ and on its homepage there is a link to information about “California Rights.”

Can Customers Delete Their Personal Information?

If DTC genetic testing customers decide to close their accounts, they will no longer be 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, however, that their personal information will be disappear.

For one thing, when customers have shared their DNA results, family trees, or other personal information with other customers, or posted information about themselves where any customer can see it, such as in a forum on the company’s website, it’s not possible to remove it. Furthermore, information that customers agreed to provide for research projects will be retained if those projects are completed or, in some cases, are still underway.

23andMe notes that while customers’ personal information and genetic samples are generally discarded when they delete their accounts, it may be obliged to keep some information about them, including their genetic information, to comply with certain laws and certification requirements.¹³⁹

Requests to discard genetic samples may be separate from requests to close the account. For instance, Ancestry explains that customers can request that their DNA data, including derivative

¹³⁶ <https://www.23andme.com/about/california-privacy/>.

¹³⁷ <https://www.ancestry.com/cs/legal/privacystatement>.

¹³⁸ <https://www.myheritage.com/privacy-policy>.

¹³⁹ <https://www.23andme.com/about/privacy/>, section 5.d.

information such as ethnicity estimates and genetic relative matches, be deleted from its system, there is a separate process for requesting that their genetic samples be destroyed.¹⁴⁰ That is also the case with FamilyTreeDNA¹⁴¹ and MyHeritage.¹⁴²

HomeDNA does not make its policies concerning data deletion clear. Its privacy policy says that customers can withdraw consent for “processing” their data and that they may have the right to request erasure of their data “in accordance with applicable data protection laws.” There is no federal law in the U.S. that provides that right. It also notes that it may be obliged to retain some customer data by law. The company says that in tests that are conducted for non-legal, non-chain of custody purposes, it stores genetic samples for 6-8 weeks “or according to contractual and legal requirements if longer.”¹⁴³

LivingDNA’s privacy policy says that customers can ask for their genetic samples to be destroyed and still maintain their accounts, but they will not be able to receive updated test results (its laboratory may retain their data but will no longer link it to them). Requesting that one’s account be shut down is a separate process.¹⁴⁴

We believe that genetic samples should automatically be destroyed when customers’ close their accounts. If they must be retained for legal or certification purposes, they should be de-identified and discarded as soon as possible. Companies should make their policies and instructions regarding data deletion clear to customers.

Most DTC Genetic Testing Companies Attempt to Restrict Consumers’ Rights and Recourse

As is typical of most consumer services, the DTC genetic testing companies we studied attempt to limit their liability in a variety of ways. For instance, Ancestry’s Terms and Conditions state that except as otherwise specified, its services are offered on an “as is” basis, that it is not liable to pay certain types of damages, and that users agree to hold it harmless for problems such as damage they cause to others as a consequence of content they have uploaded to the company’s website.¹⁴⁵

The other companies have similar provisions in their terms, except for LivingDNA, which is based in Europe and whose terms are generally much more consumer-friendly. It attempts, “to the extent permitted by law,” to limit its liability to any “foreseeable loss or damage” it has

¹⁴⁰ <https://www.ancestry.com/cs/legal/privacystatement#deletion>.

¹⁴¹ <https://www.familytreedna.com/legal/privacy-statement>, section 7.F.

¹⁴² <https://www.myheritage.com/privacy-policy>, How do you delete information about yourself or your family?

¹⁴³ <https://homedna.com/privacy>, sections 5 and 6.

¹⁴⁴ <https://livingdna.com/legal/Privacy-Policy>, Part D.

¹⁴⁵ <https://www.ancestry.com/cs/legal/termsandconditions#warranty>, sections 5, 6, and 7.

caused, up to a certain monetary amount, but acknowledges that it does not “exclude or limit in any way our liability to you where it would be unlawful to do so.”¹⁴⁶

It’s important for consumers to know that despite provisions in companies’ terms of service regarding warranties, liability and indemnity, they may have rights under state or federal law. Exercising those rights, however, is another matter.

All of the companies we studied except LivingDNA limit customers’ ability to go to court in the event of a dispute that cannot be resolved to the consumers’ satisfaction informally. The terms of service for 23andMe,¹⁴⁷ Ancestry,¹⁴⁸ FamilyTreeDNA,¹⁴⁹ and HomeDNA¹⁵⁰ require consumers to submit to binding arbitration provided by private entities of the companies’ choosing. MyHeritage does not require arbitration, but its terms of service state that all disputes will be governed by the laws of the State of Israel, lawsuits may only be brought in that country, and consumers waive the right to participate in class action lawsuits. This makes it highly impractical for U.S. consumers to sue the company. Waivers of the right to participate in class action suits or to file arbitration claims collectively are commonly found in the terms of service, and while consumers may be allowed to bring individual actions in small claims courts, sometimes they are required to do so in the state in which the companies are located, or as the MyHeritage example illustrates, in another country. Even in cases where this may be feasible, small claims court is not the appropriate venue for addressing systemic problems with companies.

Consumers who are forced by terms of service to initiate binding arbitration are often obliged to pay significant filing fees (in the Ancestry terms of service, they are responsible for up to \$250, and if the fee exceeds that, the company will reimburse them for the balance). Arbitration may also entail expenses for legal representation and travel, which are not necessarily reimbursed to consumers. As a study¹⁵¹ that the Consumer Financial Protection Bureau conducted about mandatory arbitration in financial service contracts showed, few consumers are likely to initiate arbitration, and even fewer obtain favorable decisions. There are only a small number of arbitration firms, and since they rely on companies choosing them to provide the service, they may be predisposed to find in their favor. Another issue with arbitration is that, unlike a court procedure, it is private; the decisions that are produced are not publicly available and set no precedent for how similar situations should be dealt with.

While not illegal, we believe that mandatory binding arbitration and class action waivers are unfair because consumers may not get the redress they deserve and are unable to appeal the

¹⁴⁶ <https://livingdna.com/legal/Living-DNA-terms-of-service>, section 18.

¹⁴⁷ <https://www.23andme.com/about/tos/>, section 28.

¹⁴⁸ <https://www.ancestry.com/cs/legal/termsandconditions#disputes>, section 10.

¹⁴⁹ <https://www.familytreedna.com/legal/terms-of-service>, section 23.

¹⁵⁰ <https://homedna.com/terms>, section 14.

¹⁵¹ *Arbitration Study, Report to Congress Pursuant to the Dodd-Frank Wall Street Reform and Consumer Protection Act §1028 (a)*, Consumer Financial Protection Bureau (March 2015), available at https://files.consumerfinance.gov/f/201503_cfpb_arbitration-study-report-to-congress-2015.pdf.

decisions. Furthermore, these terms prevent consumers from taking effective action to hold companies accountable for privacy violations, data breaches, misleading advertising, defective products or services, or other systemic problems, and to change their future behavior. Some companies allow consumers to opt-out of the arbitration requirements by sending a notice that they wish to do so within a certain number of days of first using the service.¹⁵² However, as we observed previously, few people are likely to read or understand the terms of service. Moreover, most people probably don't even think about the possibility that they may want to take legal action until and unless a serious issue develops, which is unlikely to occur within the short time that is provided to opt-out of arbitration. It's a safe bet that few DTC genetic testing customers ever opt-out.

Mandatory binding arbitration and class action waivers are not only found in terms of service for genetic testing; these provisions are increasingly showing up in the terms for many different types of products and services. Regardless of the limits and restrictions in the terms of service, consumers should try to resolve problems directly with the company if possible. If that does not work, consumers can make complaints to their state or local consumer protection agencies.¹⁵³ They may be able to resolve individual problems and even take formal legal action against companies if they believe that is warranted. Consumers can also report problems with companies to the Federal Trade Commission at <https://reportfraud.ftc.gov/#/assistant>. While that agency does not resolve individual complaints, it can take action to stop unfair or deceptive acts or practices. Consulting with an attorney who specializes in consumer law is also an option, even though a class action may not be possible. The National Association of Consumer Advocates is a good resource, <https://www.consumeradvocates.org/>.

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,¹⁵⁴ 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,

¹⁵² See, for instance, <https://www.23andme.com/about/tos/>, 28.e.

¹⁵³ To find them go to <https://www.usa.gov/state-consumer>.

¹⁵⁴ 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>.

however, and because the results may not be accurate they should not be used to diagnose or treat health conditions.¹⁵⁵

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.¹⁵⁶ 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.

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.

¹⁵⁵ 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.

¹⁵⁶ 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/>.

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.