

Giving DNA Test Kits as a Gift? Who Owns Your DNA Data?

In 2017, people bought more DNA test kits than in all other years that they have been available. Ancestry.com topped their previous sales records within the four days of 2017's Black Friday and Cyber Monday. I found that there is a right way to obtain a DNA test and an extremely wrong way.

Our DNA data belongs to us individually. We have a right to own this data and to know what happens to it when we order an online DNA test kit. The gift of helping you find out where you came from and the possible discovery of living relatives are powerful selling tools for companies like Ancestry.com and 23andMe.com. They lower their [DNA test kit prices](#) during the Black Friday, Cyber Monday, and December shopping frenzies.

Deoxyribonucleic Acid

[Fredrich Miescher](#), a Swiss doctor, became the first researcher to examine what eventually became known as DNA in 1896 in a medieval castle kitchen. Dr. Miescher named it nuclein. [James Watson and Francis Crick](#) announced in 1953 that they had found the structure of DNA which was a double-helix polymer. And so began the search for the discovery of life—and today we know how important DNA is to science, health, forensics, genetics, and the pursuit of discovering your ancestors through genealogical research.

What Can You Learn from a DNA Test?

The Three Common Categories for Consumer DNA Tests

Autosomal DNA:

- Most common
- Covers 22 of the 23 chromosome pairs
- Determines traits of ethnicity, ancestry, and disease susceptibility/wellness
- Inherited from both parents
- Available to men and women

Y-chromosomal DNA (Y-DNA):

- The 23rd pair of chromosomes determines if we are a boy or a girl
- We inherit an X chromosome from mother, and either an X or a Y from father
- Useful for ancestral genetic testing
- Only available to men because women have no Y chromosomes

Mitochondrial DNA (mtDNA):

- Makes up a tiny proportion of the human genome
- Only investigates the ancestry of the mother.
- Traces maternal lineage through hundreds of potential generations
- Available to men and women

DNA Testing Advice from the U.S. Federal Trade Commission

If you're thinking about buying a kit for yourself or a family member, the FTC has advice about protecting the privacy of the sensitive information that DNA tests reveal.

We've brought dozens of cases challenging deceptive or unfair practices related to consumer privacy and data security – including a settlement with a business that sold products based on at-home genetic testing, but allegedly failed to provide reasonable security for consumer's personal information. (4)

Digging Up Bones

Ancestry.com

I mine tons of information for historical research purposes. I frequently use three of the nine brands owned by Ancestry.com, but I do not subscribe to any of them. You can purchase services from their ProGenealogists, subscribe to Fold3 for military records, Newspapers.com, Ancestry.com, and Archives.com, and buy their DNA test kit. FindaGrave.com, Rootsweb.com, and Ancestry Academy videos are free.

Ancestry.com uses Quest Diagnostics for their DNA testing. Quest Diagnostics carries a [disreputable and controversial reputation](#) with consumers and employees worldwide. In Ireland, they [misdiagnosed](#) cervical cancer and sparked a government inquiry. In the U.S., Quest misdiagnosed vitamin D deficiencies for two years. The high percentage of negative employee reviews for Quest Labs on [Indeed.com](#) speak for themselves. I watched short videos on YouTube of people reviewing their Ancestry.com DNA tests. One lady's father was 40% Italian, and she had no Italian DNA according to their tests. (8)

New York Attorney, Joel Winston, practices consumer protection law and advises people to pay close attention to Ancestry's privacy policy and terms of service. He cites three significant provisions that consumers should [consider before testing through](#) Ancestry.com:

- The perpetual, royalty-free, world-wide license to use your DNA
- The warning that DNA information may be used against "you or a genetic relative"
- Your waiver of legal rights

The Ancestry Academy videos are notably informative.

23andMe.com

23andMe.com employs [LabCorp](#) as their DNA testing company. LabCorp holds mixed employee reviews on [Indeed.com](#) with numerous five to three-star ratings. The Better Business Bureau closed 411 consumer complaints on LabCorp in the last three years. I did not find news reports of misdiagnoses.

When you order a DNA kit from 23andMe.com, you give them the required information. Then, 23andMe.com tracks and collects all your online details via social media, web beacons, and your IP address. It compiles your personal photos, employment information, and a record of every website you click on, plus it conducts real-time tracking of your location.

If I put 23andMe.com on the Let's Make a Deal stage, you would see 23andMe.com as a DNA health and ancestry information provider behind Curtain Number One. Behind Curtain Number Two, you would see a huge storehouse filled with millions of consumer's data from around the world piling

up daily. Curtain Number Three would reveal the hundreds of companies who are purchasing personal consumer data from 23andMe.com. This big data warehouse company presents you with a 2,670-word Research Consent Document with seven key points that looks completely open and honest about their intentions of sharing your data.

Upon reading the [fine print](#), consumers will find a provision that allows 23andMe.com to unilaterally modify its privacy policy at any time which changes the limitations on the consent document that consumers agreed to. This means that 23andMe.com can modify its policy to sell consumer data without consent. In 2016, Google Ventures, with Bill Maris as managing partner, invested in 23andMe.com. Maris replied to objections with, “What are you worried about? Your genome isn’t really secret.”

The HIPAA (Health Insurance Portability and Accountability Act) Privacy Rule does not apply to consumer curation of health data or any associated protections related to privacy, security, or minimizing access. HIPAA laws only cover curation of consumer health data if a company receives funding from a federal agency like the National Institutes of Health (NIH). Guess what? [23andMe.com receives NIH funding](#) but claims its de-identification process exempts them from compliance with HIPAA’s Privacy Rule.*

Currently, 23andMe.com sells data from their DNA customers to third-party companies, research institutions, and non-profit charities.

Great News! Easy Access to Reputable and Reliable DNA Testing Labs

Advertising professionals do not consider laboratories pretty and easily dressed up for commercial sales like most retail ventures. Laboratories do not normally set a huge advertising budget. Yet, consumers set a DNA test kit sales record in the 4th quarter of 2017 because the popular DNA test vendors like Ancestry.com and 23andMe.com dress up with a seductive advertising wardrobe that costs millions of dollars.

During my recent research for this subject, I found too many sites comparing the “popular” DNA testing company services which amounted to another sales campaign for all of them that left out critical information. The best advice I found on how to purchase a DNA test comes from an article on the Genetics

Digest website by a team of writers and scientists passionate about all things DNA. The Genetics Digest article, "[3 Mistakes to Avoid When Shopping for a DNA Test](#)", is a must-read before you buy that popular DNA test kit wrapped up in a mink stole.

Here is what you will learn from this reputable, information-packed, five-minute read:

- How DNA tests work
- Why many are not good quality
- How to select a good DNA test
- Where to get a great DNA test
- Mistake #1:
Don't buy a brand by how "popular" it appears to be
- Mistake #2:
Don't buy the cheapest OR the most expensive DNA test you can find
- Mistake #3:
Confusing "Accuracy" with "Precision."

The Genetic Icing on the DNA Cake

[23andMe.com](#) has sued Ancestry.com for copyright infringement and deceptive advertising. This lawsuit is still in the works.

[3 Mistakes to Avoid When Shopping for a DNA Test:](#)

At Genetic Digest, we're consumers too and we want the best deals on the highest quality goods at the most reasonable prices as much as anyone else. When all of our senses are constantly bombarded with advertising at every moment of every day, it's hard to tell which deals really are the best and which products really are high quality.

Notations

*[De-identification](#): De-identified patient data can be used to improve care, estimate the costs of care, and support public health initiatives. Scientists have

been using de-identified data for years. HIPAA lists 18 direct identifiers that are typically present in patient medical records. De-identified patient data is health information from a medical record that has been stripped of all direct identifiers.

