

Privacy and DNA Testing-October 2019

When and if you decide to take a DNA test it is important, very important, to read the information your chosen testing company is providing about what they do with your sample. Some of the companies keep your sample so it is available for other DNA tests. FamilyTreeDNA (ftdna.com) offers three different tests, Y-DNA, mt-DNA, and at-DNA, and all the tests can be from one sample. Some companies discard the sample, and others keep the sample for future use, but only with your consent.

Do not click ‘agree’ to any question without reading the terms of service.

Taking a DNA test can reveal unexpected information about the test taker’s immediate family, ancestors, or descendants. Findings such as misattributed parentage, adoption, and unknown family, can be upsetting, a great joy, or both.

When it comes to DNA tests, a lot of pertinent information hides in the fine print, including language about who owns your DNA, where your genetic information is going, and what the process of deleting your information from a database involves. Also, you can indicate who will inherit your DNA results.

Each testing company asks the new test taker a series of questions to establish their account, such as, do you want to share your DNA results, do you want to know who you match, how do you want to be identified (your real name, nick name, initials or fictional name), or do you want to list your contact information.

Choose account options carefully. You can start out with your account more protected, and as you learn more and become more familiar with how the sites operates, you can revisit your choices.

23andMe and Ancestry both have research partnerships with pharmaceutical companies that explore things like the genetics of aging, psychiatric disorders, or inherited diseases. Both companies require you to consent to sharing your information if you want to participate in those programs. Unless you agree, your information will remain with just 23andMe or Ancestry and the contractors they work with to do the test.

The rise of consumer genetics tests has brought up several privacy concerns, since they deal with information that’s fundamental and unique to every individual. There have been cases like the arrest of the Golden State Killer, which used information from a DNA sharing database site (GEDmatch) to crack the case. GEDmatch, which is not a testing company, allows people to upload their DNA test results to their database to share with other people who have tested at other testing companies. At this time the tester must agree to have their results shared with law enforcement. FamilyTreeDNA has recently allowed law enforcement access to their database. Again, the tester has to agree to participate with the law enforcement program.

Again, read the fine print, understand what your chosen testing company does, and who owns your DNA. Each person needs to determine what their comfort level is regarding sharing their DNA results.