There are many things to consider before you have genetic testing, especially if ordering a test online without your doctor. Several companies sell DNA testing directly to the public, and the types of testing and services differ. The questions here apply to DNA tests, also called genetic tests, including health-related and ancestry. (Paternity testing, another type of DNA test that can be ordered through a doctor or at home, is not addressed here.)

Keep in mind:

- You should be able to ask questions. Reliable companies put contact information on their website and marketing materials.
- A certified genetic counselor can help you think about what is important in making decisions about genetic testing: To find a genetic counselor near you, visit www.findageneticcounselor.com.

1. **What do I need to ask to make sure the test is accurate and reliable?**

There are two key parts to answer this question:

- Does the testing lab meet quality standards?
- Is the staff qualified?

In the United States, this means ask if the lab has CLIA, CAP, or AABB certification. These certificates show a lab meets certain quality standards required to offer testing. Many people ask whether or not tests are “FDA approved.” That question is a bit more complicated, because the FDA has approved some, but not most, genetic tests. The FDA is still developing plans to address genetic testing.

Ask the company offering the test about the educational background of the people who work at the company because genetic test results are not always black and white. A quality test usually comes from a place with a team of experts like certified genetic counselors, medical geneticists, pathologists, Ph.D. geneticists or biologists, and molecular pathologists.

2. **What will the test tell me, and how will I find out?**

Genetic test results can be complicated – whether you order it at home or through a doctor - so before ordering a test, find out what to expect. You might ask first:

- What’s being tested: health conditions, ancestry, traits, or drug responses?
- How will I find out my results?
What will I do with my results, and will they help me make health decisions?

Will I find out extra information that I might not be expecting?

Will I need to share my results with members of my family?

Some DNA tests are straightforward; they tell you whether you have a health risk or tell you about family relationships. Other results may be accurate but not necessarily useful. Some results fall into a “gray zone,” because it isn’t always clear what they mean. Most tests don’t include all the genes that might affect your health. Sometimes people discover “extra” information that they were not expecting. That’s because our DNA can tell us a lot—about our health, health risks, and even our families.

3. If new information is discovered that could change my results, will the company let me know?

New discoveries are being made daily. We are born with our unique genetic code (our DNA), yet the understanding of DNA continues to improve. With more information, the meaning of your test result may change over time.

Ask your online genetic testing company if they will recontact you if there is new information about your results. Some may send an email notification, update their website, or have staff contact you directly. Others may not plan to contact you. It’s important to know if and how the company will let you know changes as the science improves.

4. How will my personal information be protected? Could it be shared?

Companies should make their privacy and security policies clear. These policies may change over time, so here are some questions to ask before you decide to test:

What do you plan to do with my genetic information, both now and in the future?

What will the company do with my genetic information? Will you share my genetic information with others, like drug or biotechnology companies, researchers, not-for-profit groups, or public or private DNA databases?

Will any DNA data shared have my information with it (such as name, date of birth, or gender)?

Will you tell me if your policies change, or if my data is shared?

Everyone’s genetic code is unique to them, so even though it is unlikely, there is a chance you could be identified based on your DNA. Some laws, like the Genetic Information Nondiscrimination Act (GINA), were written to protect most people from health insurance companies and employers using your genetic or family history information against you. The Affordable Care Act of 2014 (sometimes called “ObamaCare”) adds another important
protection because health insurance companies are no longer able to deny, charge more, or refuse treatment coverage for people with an existing health condition. There are many additional state and federal laws as well. While these laws are not specific to online DNA testing, it is important to know that they exist for your protection.

5. Are trained professionals, like genetic counselors, available to help me?

Before you order a test, ask if the company has or can send you to a specialist to ask questions, get support, or be connected with other resources. Questions to ask are:

- Will a trained professional, like a genetic counselor, be available before or after testing?
- Is this service included with the cost of testing?
- Are they employed by you or a separate service?
- If you don’t have trained genetics professionals on staff, do you have a referral network?

Some people receive results that are unexpected, surprising, disappointing, or confusing. Other people receive results that are useful and might help them with medical decisions. Having a qualified professional to help you understand your results is an important step in making sure you get the most benefit from your test.

To learn more about questions to consider before ordering genetic testing or to contact a genetic counselor, visit [www.nsgc.org](http://www.nsgc.org).