

Direct to Consumer Genetic Testing: What You Need to Know

What are you paying for? What happens with your data?

	STANDARD (CLINICAL) GENETIC TESTING	DIRECT TO CONSUMER GENETIC TESTING
PURPOSE	To diagnose or confirm suspected genetic conditions, assess risk for hereditary diseases, or identify carrier status.	To provide information on ancestry, traits, and general health predispositions. Results are not considered diagnostic.
ORDERING PROCESS	Ordered by a healthcare provider or genetic counselor.	Ordered directly by the consumer, no healthcare provider involvement required.
TEST SCOPE	More comprehensive, typically looking at the entire gene for sequence variations, deletions, and duplications. Focused analysis.	Broader testing of limited variants, or genome wide associations. Can be less reliable for medical implications.
SAMPLE COLLECTION	Typically blood, saliva, or buccal swab collected in a clinical setting.	Usually, saliva or cheek swabs are sent by mail after ordering kit online.
ACCURACY AND RELIABILITY	More accurate for diagnostic purposes.	Results may not be definitive. Can be less reliable
RESULT INTERPRETATION	Results are interpreted by a genetic counselor or medical professional with genetics knowledge.	Results are often presented in a report, can be difficult to understand without clinical genetics training.
PRIVACY & DATA USE	Governed by HIPPA and medical privacy laws, data stored securely within medical records.	Data privacy policies vary; companies may share or sell data with third parties.
FOLLOW UP & SUPPORT	Results are integrated into electronic medical record, follow up testing and medical interventions may be recommended.	Follow up requires individuals to organize medical care independently. Providers may not accept referrals related to direct-to-consumer genetic testing due to uncertainty of results.
COST	Can be covered by health insurance if medically necessary. Out-of-pocket costs vary widely depending on the test, although many clinical laboratories offer financial assistance programs.	Typically, lower cost (\$50-\$300).
TURN AROUND TIME	2-8 weeks depending on the laboratory and complexity of the testing.	2-6 weeks after sample received.
TEST EXAMPLES	Invitae/LapCorp, GeneDx, Myriad Genetics, Quest Diagnostics	23andMe, AncestryDNA, MyHeritage DNA

1. **The results are not diagnostic.** Genetic tests scan genomes for variations that are known to correlate with increased risk for certain diseases, such as Alzheimer's or diabetes. But they don't predict an individual's chances of getting those illnesses. "It's population-level data," says Erby, noting the genetic analysis doesn't take into account factors such as race or lifestyle. Some direct-to-consumer companies offer genetic counseling for an additional fee, but in general customers receive little guidance about what the results could mean for them.
 - a. Main take away is testing doesn't predict an individual's chances of getting those illnesses.
2. Some genetic testing companies **sell the information they gather** to third parties, primarily for research. And with a court order, the information can be obtained for investigative detective work like the sleuthing that led to the arrest of the Golden Gate Killer in 2018.
 - a. Reading the fine print is important. Find out if the company sells their data to third parties.
3. Some companies offer to test children for athletic or academic aptitude, raising **questions about pediatric consent** and who owns a child's genetic information. What's more, the results are loosely reliable at best and don't provide a comprehensive evaluation, measuring factors like a child's interest or education.
 - a. Be cautious about genetic testing for children. Could be a slippery slope if one parent wants testing and other parent does not. Also, consideration of if the child's genetic information will go to a third party. What are the ramifications of this?
4. **Ancestry tests** can provide interesting information about a person's genetic makeup, but the accuracy and precision vary by company.
 - a. This information can be used for fun but understand that the information may not be 100% accurate or precise. You can do your research on the company to better understand their methodologies.
5. **Results can influence your insurance.** Employers and health insurance companies are not allowed to discriminate based on genetic information, but companies that sell life, disability and long-term care insurance have no such constraints. They typically consider genetic test results such as increased risk for diabetes or cancer when determining cost and coverage. Yet, says Mathews, "people are not prompted to think about how their access to insurance might change."
 - a. Be aware that insurance companies (life, disability and long-term care insurance) have no constraints to change premiums and limit insurance plans based on your genetic information.

Bottom line: Read the fine print and proceed with caution.

- Review the pros and cons of genetic testing. Why do you want to have genetic testing? What purposes will the results serve? Be sure to research the company performing genetic testing. Is it a reputable company? Do they sell your data to third parties?

Source: <https://www.hopkinsmedicine.org/news/articles/2018/03/five-things-to-know-about-direct-to-consumer-genetic-tests>