

Facts About Direct-to-Consumer Genetic Testing

Genetic testing is more available than ever before. Many genetic tests are ordered by a medical provider but some genetic tests can be done on your own. You collect your own sample, mail it to a testing company, and pay for it yourself. Then, results are sent straight to you. These tests are advertised to consumers and are called “direct-to-consumer” or “at-home” genetic testing.

WHAT CAN I LEARN FROM DIRECT-TO-CONSUMER GENETIC TESTING?

There are different reasons people consider taking direct-to-consumer (DTC) tests. DTC testing may offer insights about ancestry, paternity, and common genetic traits. However, DTC tests are different from genetic tests ordered by a healthcare provider. DTC testing is not intended to identify medical health risks or diagnose genetic conditions. The results do not take into account your personal health and family history, both of which can be important for understanding your unique genetic findings. In addition, some DTC companies may offer “raw data” to their customers. The raw data includes genetic information that has not been interpreted by the testing laboratory. Online sites offer to interpret the raw data and provide a report of genetic risks; however, these sites are not regulated. Risk prediction using this raw data is not validated and may not be accurate.

HOW CAN I FIND OUT ABOUT FUTURE HEALTH RISKS?

Understanding your risk for future health problems is complex. If you have specific questions about genetic risks and your medical health, talk with your medical provider before doing DTC testing. Your medical provider can offer genetic tests based on established guidelines, such as routine genetic carrier screening for pregnancy planning. In some cases, specialized genetic testing may be ordered to look for uncommon DNA changes known to cause medical problems. Finding these types of changes can help guide your medical care or allow testing of other family members. DTC testing is not designed to provide this type of information.

WHAT ARE THE CONCERNS ABOUT DTC GENETIC TESTING?

- Many DTC tests are based on **limited scientific data**, so results may be misleading or inaccurate. Testing could show a risk that is not real or give reassurance when there really is a risk.
- DTC tests give an **incomplete** picture of your genetic make-up.
- Results are unlikely to provide clear explanations for current health issues or accurately predict future health risks.
- **More research is needed** to understand minor variations in DNA.
- Your DNA is like a fingerprint and your **privacy may not be protected** by DTC companies.

IF YOU ARE CONSIDERING DTC TESTING:

Make sure:

- ...you know what the test is able to tell you.
- ...the scientific evidence for the test is clearly stated.
- ...you ask what happens with samples after testing and how your privacy is protected.
- ...the testing company has a qualified genetics expert available to help with ordering and interpreting results.
- ...the laboratory is CLIA certified (Clinical Laboratory Improvement Amendments) or has a State-based certification to ensure quality control.

For more information about direct-to consumer testing:

Genetics Home Reference – What is direct-to-consumer genetic testing?

<http://ghr.nlm.nih.gov/handbook/testing/directtoconsumer>

References:

Direct To Consumer Genetic Testing, NSGC Position Statement, 2007, Revised 2015
ACMG Statement on Direct-to-Consumer Genetic Testing, 2008, Revised 2016