

Direct to Consumer Genetic Testing

(DTC Testing)

What is DTC testing?

DTC testing, also known as at-home genetic testing, refers to genetic tests available directly to consumers without the involvement of a health care professional. To date roughly 40 companies sell DTC tests that look for over 1700 health and medical conditions.

How is DTC done?

Typically customers pay a fee and receive a kit in the mail to collect a DNA sample which they send back for analysis. Results are usually delivered online or by e-mail back to the customer.

Why consider DTC testing?

Familial lineage and disease risk are some of the reasons for undergoing DTC testing. The results can provide information about ancestry, paternity and ethnicity. Some providers will even determine the percentage of an individual's genetic makeup that descends from Neanderthals.

Consumers can also access DTC tests to identify a genetic predisposition to diseases such as Alzheimer's, diabetes and cancer. Other tests point to potential allergies, responses to medications, risk of cardiovascular disease, etc.

The provider of the genetic test can provide useful information including lifestyle changes that may improve health and prevent disease, as well as general education about disease risk.

Limitations of DTC testing

While genetic tests are becoming easier and cheaper to carry out, scientific validity remains a

key issue as the interpretation of genetic tests is complex. Experts suggest that such tests show promise for the future, but do not currently yield results consumers always can rely on. For example, the same DNA samples tested by different companies can in some cases generate contradictory results and predictions that conflict with any existing medical conditions.

Apart from a small number of single gene disorders, such as Huntington's, most disease-related analyses test for susceptibility and thus clinical utility remains in question for DTC testing. The relationship between a genetic trait and the onset of disease is complex and subject to many different genetic and environmental factors. The connection between test results and subsequent disease outcomes is not straightforward.

Ethical Issues

When health-related services become commodities, conflicts may arise between consumers' best interests and DTC companies' profit motives. Consumers need accessible and reliable information to make appropriate decisions and protect their own best interests, but there remains a lack of information for consumers on the scientific validity and clinical utility of DTC genetic tests. Companies vary widely in the amount and quality of information they make available about the scientific basis for their testing services. As well, high literacy levels – typically, college-level reading skills – are required to understand the information provided.

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Genetic testing has traditionally been provided within the context of genetic counselling; many DTC companies do not offer such counselling beyond what is written on their websites, or only provide counselling at an additional charge or at the customer's request. Genetic susceptibility is a complex matter, involving not only the customer, but also his or her family, who may share genetic susceptibility, and requires information and advice that is based not solely on test results but also on the individual's own particular situation. It is almost impossible to ensure that information given via mail or electronically has been properly understood by the customer.

There are privacy issues around the collection, use and retention of genetic samples. Questions have been raised around the ownership of genetic material, particularly if a company goes bankrupt or otherwise out of business. Many companies facilitate social networking by permitting customers to share their genetic results online with family and friends and participate in company sponsored blogs, which also raises privacy concerns.

More Information and Resources

<http://www.theglobeandmail.com/life/health-and-fitness/health/genetic-self-testing-kits-to-come-to-canada/article20885678/>

<http://www.theglobeandmail.com/life/health-and-fitness/health/genetic-testing-may-encourage-unrealistic-expectations-research-says/article28949637/>

<http://www.nature.com/scitable/topicpage/DTC-Genetic-Testing-for-Diabetes-Breast-Cancer-698>

<http://www.economist.com/news/business/21590941-regulator-brings-genetics-company-halt-and-fda?zid=314&ah=607477d0cfcfc0adb6dd0ff57b8e5c9>

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