

Direct to Consumer Genetic Testing – Good or Bad?

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### Abstract

Genetic (DNA) testing has become commonplace in today's society. It is on every TV drama and many talk shows. Just a simple swab and the test can reveal who the "baby daddy" is. Test kits are available over the counter or Internet for a variety of costs. The results are made available to the consumer. But do these results belong in the consumer's hands? Should they be sent to a health care professional for interpretation? Will these results cause undue stress on the individual? The debate continues on whether these tests should be available to consumers and at the same time the price to that consumer is going down, making it much easier to find out what the DNA will reveal.

#### Direct to Consumer Genetic Testing – Good or Bad?

Genetic testing is a voluntary test. It identifies changes in chromosomes, genes, or proteins. Many times these tests are done to determine if a certain disease or disorder can be passed on or inherited by future generations. Getting a genetic test is a very complex decision to make because there are many pieces of information involved. Because this information is so complex, a genetic counselor should be used to interpret the results of the tests. This, however, is not a requirement of the test.

At the website, 23andme.com, one can find out all kinds of things about themselves such as ancestry, disease risk, drug response, and carrier risks for offspring. It is a simple process. Simply order the kit from the online store, spit in the cup, send it in and get the results. For \$99 they will deliver the kit to the consumer, the consumer agrees to pay a \$9 a month service charge for a year (an additional \$108) to get monthly updates about their DNA and the results are posted so the consumer can read them online. But what happens if the consumer finds out there is a disease that has been dormant for several generations in their DNA? Does that consumer worry

himself to death wondering if he will get the disease? How does the consumer handle this information? Should this information be available to the consumer or should it be sent directly to a health care professional? The information at 23andme.com says that they do not diagnose disease but they will help with possible responses to certain drugs.

The Personal Genome Service® helps you identify potential health risk factors, highlights interesting traits and explains the impact of genetics on metabolism of drugs and how that could impact you. The service also sheds light on genetic factors for conditions you may pass on to your children. Beyond the powerful information on your health and traits, the Personal Genome Service® includes a relative-finding discovery engine and tells you about your ancestry.

(23andme.com, 2012).

Even though the lab that 23andme.com uses for their testing is a reputable lab that many doctors use, there is no guarantee that the patient will or will not contract a disease for which they have the gene. Gregory Kutz, Managing Director, Forensic Audits and Special Investigations United States Government Accountability Office, in testimony to the Committee on House Energy and Commerce Subcommittee on Oversight and Investigation stated that “many experts remain concerned that the medical predictions contained in the results mislead consumers. (Kutz, 2010).” The results of DNA testing can be very difficult to understand and interpret. Many argue that a health care professional is needed to interpret and read the results so as not to confuse the consumer. Many diseases have no cure and no means of slowing down or preventing the disease such as Parkinson’s disease. To date there are no government guidelines to direct consumers to employ a healthcare professional to interpret the results for them.

Matt Bower, a genetic counselor at the University of Minnesota Medical Center, Fairview, in Minneapolis says that just because a person has the gene for a certain disease does not mean that the person will actually get the disease or vice versa. Misreading of these tests can lead to misleading health changes. If a person sees that they have the gene for a certain disease, this can cause undue stress on that individual worrying that they may get the disease when it is entirely possible that they never will.

On the other hand, it can make the patient aware that they might get the disease and early testing and more frequent testing can be done to detect the disease as early as possible. The patient can be on the lookout for any early symptoms. Early detection is one of the good points of DNA testing. Some people are carriers of the disease and will never contract the disease. However, the carrier can pass on the gene to future generations. In families with high risk of an inherited disease, the test could relieve those who do not have the gene.

The results of DNA testing are only part of the issue. It is widely known that cigarette smoking is harmful to health, but that is not making people quit smoking. Everyone knows that a sedentary lifestyle and obesity can shorten their lives, but it does not seem to be changing their lifestyles. Many diseases may be impacted by diet, lifestyle and environmental concerns. Many of these issues can be controlled by a strict diet and avoiding certain foods. These kinds of tests can be life changing and can save lives. A biochemical test can reveal some of this.

Biochemical tests look at the amounts or activities of key proteins. Since genes contain the DNA code for making proteins, abnormal amounts or activities of proteins can signal genes that are not working normally. These types of tests are often used for newborn screening. (<http://www.genome.gov/19516567>, 2012).

The reverse is that a disease can be contracted by someone who has no genetic predisposition for a disease. If the gene is not present, this could cause the person to have a false sense of security that they will never contract that disease. The controversy continues on this matter as well as developments of new types of testing.

It has been suggested that the general public needs more education in genetics before these tests can become relevant. It has also been said that even some doctors do not have the ability to analyze and use the tests accurately. The more advanced the tests become, the more difficult they will be to read and interpret, thus making it almost imperative that a healthcare professional be used for advising how to relate to the results.

Another issue that may need to be addressed is insurance and how these tests might influence actuarial results. In one study the results of a DNA test revealed that the patient had a gene which could lead to contracting a serious disease. In a consultation with the patient's doctor, the doctor warned the patient not to put this in his medical records. The doctor explained to the patient that the reason for this is if the patient happened to lose his job and tried to get insurance with another company, this information could be construed as a pre-existing condition, even if the patient did not have the disease. Even though the Genetic Information Nondiscrimination Act of 2008 (effective November, 2009) states that no one can be denied coverage because of genetics. If this information is put into medical records and a health issue is discovered, there is no provision in the Act that covers this (Youso, 2010). Even life insurance could be denied, jobs can be affected as well as credit denied.

Although there are reputable companies doing consumer testing of DNA, there are still those out there who do not have the best interest of the consumer in mind. Many of the test results have been sent to consumers with instructions for a better lifestyle that are well known

accepted health guidelines, such as a change in diet and exercise. Some companies have recommended high cost health treatments that were no more than a simple over-the-counter multi-vitamin supplement. Other companies use the information gathered to sell information on ways to delay or depress a possible disease. These companies have been proven to be unreliable and the information given to the consumer is either not accurate or completely bogus (Kutz, 2010).

Genetics professionals should be enlisted to help counsel, diagnose, or discuss any genetic risks that might arise through genetics testing. The subject of genetics testing is very broad and very specific and an expert in this subject is definitely warranted if the choice for genetics testing is made.

### Conclusion

Consumer DNA testing has been available for several years but the debate continues among healthcare professionals and government officials whether this is a good idea or not. As the tests get easier to get and more affordable, more people will opt to get these tests without adequate education, research or proper counseling from a professional. Some laws have been put in place to protect consumers against using this information against them, but much work is still needed on defining what needs to be added to protect the consumer against discrimination by those who might receive this information by whatever means. At this time, there are no standards governing the testing, quality or accuracy of consumer testing companies so it is definitely a case of buyer beware. Even though a person may be genetically predisposed to a certain disease, disorder or syndrome, testing should be accompanied by professional healthcare counseling and education to make the information more useful to the consumer.

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