

# What Should You Look for in a DNA Test?

They're on store shelves, all over the internet, and in television ads: those DNA kits that promise a deep dive into your health and family tree. Who wouldn't be tempted?

Most of us, as it turns out.

It's estimated that more than 26 million consumers contributed their DNA to four commercial ancestry and health databases in early 2019. Some of us still hesitate, and for a good reason. Sure, we're curious, but we wonder if we're opening Pandora's box of data that we're not equipped to handle. How do we decipher our DNA results? What happens to our sample once it's out in the world?



"I get calls daily from people asking, 'Should I see you first before purchasing a DNA test?' They want to know the difference between the clinical tests we perform and the Direct-to-Consumer (DTC) tests sold in stores," says Samantha Neumann, a genetic counselor at the University of Miami Health System. "We talk through the pros and cons of DTC versus clinical tests so they can make an informed decision."

UHealth's Department of Human Genetics is one of 20 sites around the U.S. that are part of the Undiagnosed Diseases Network, a research study focused on whole-

genome sequencing, the most advanced and detailed method for evaluating our genetic code.

"Non-university centers don't have access to this Network. We're lucky to be part of it; it gives us the ability to go the extra step and provide an extra level of care," Neumann says.

## **What is the difference between store-bought and clinical DNA tests?**

Neumann, who helps people understand the complexities and nuances of their personal genetic code, explains.

"If you think of a genome (a complete set of genetic instructions) as a sentence, a DTC test looks at that sentence one way. It might find three typos. A clinical test looks at that sentence backward, forwards, inside out, and upside down. If you pick a test that only looks at 10 genes, but the answer for the condition in that family is in a different gene that was not tested for, you could miss finding an answer. We tailor our tests to every single aspect of a person, but store-bought tests are more of a 'yes/no' approach."

One thing some consumers don't consider when tossing a test into their shopping cart is how the results will make them feel.

"The generality (of a DTC test) can give you information that's disruptive to your identity, and that affects other family members," Neumann says.

Neumann and her fellow genetic counselors work with people who take the initiative about their risks for genetic conditions.

"The three main categories we address are cancer, pediatrics, and prenatal testing."

If there's a family history of breast cancer, a patient needs to know if they carry the BRCA1 or 2 gene. A young couple ready to start a family may worry about passing along a disabling family trait to a future child. Another patient seeks counseling because he has "a unique mix of medical problems and there may be a genetic component," Neumann says.

## **What happens during a genetic counseling session?**

If you see Neumann before getting tested, she will review three generations of your family health history, perform a full risk assessment, and discuss your testing plan. A risk assessment may reveal your likelihood of developing particular genetic disorders or the possibility of passing down a trait such as cystic fibrosis.

She also reviews your insurance and flags any potential for insurance discrimination. Some companies do not cover genetic testing unless you seek counseling first.

Patients can see a genetic counselor without a doctor's referral - check with your insurer for coverage, limitations, and requirements. During the pandemic, counseling was conducted via telemedicine, a convenient method some patients still use.

In an ideal world, Neumann would see patients before and after genetic testing. That's not always possible.

However, if you did at-home or clinical testing and received confusing or upsetting genetic information, "We're here to pick up the pieces on the back end," Neumann

says, referring to her ability to talk patients through their results and next steps.

Genetic counselors must have a master's degree in genetic counseling and be certified by the American Board of Genetic Counseling (ABGC). To practice in Florida, they must also be licensed by the state.

## **If you want to try an at-home test, keep these caveats in mind:**

- Be aware of how the company uses your data - there could be potential pitfalls such as identity theft or your DNA being mistakenly connected to a crime you did not commit.
- Read online reviews of the company and its testing products before you buy.
- If you get a problematic result, confirm it with a clinical test.

When considering direct-to-consumer tests, remember Neumann's perspective. "It's a medical tool but also a product. The implications of using this product are much more far-reaching than buying a bed or a lamp."

To schedule an appointment with the UHealth genetics team, call 305-2430-6006.

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