

# Genetic testing kits get closer look in Loyola study

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(Medical Xpress)—Several companies sell genetic testing directly to consumers, but little research has been done on how consumers experience such tests. The tests have raised questions about the validity and accuracy of the information provided to consumers – especially without the involvement of a qualified health-care professional.

Now a study led by a researcher at Loyola University Chicago Stritch School of Medicine is providing insight into how a diverse group of [primary care](#) patients experience [genetic testing](#).

Lead researcher Katherine Wasson, PhD, MPH, and her colleagues conducted in-depth interviews with 20 patients recruited from primary care clinics. Among the findings, published online ahead of the print edition, in the *Journal of Community Genetics*:

- Most participants thought results were fairly easy to understand – with the help of a genetic counselor (provided by the study, not the testing company). But fewer than half said they might be able to understand results on their own.
- Most participants expressed no concern or hesitation about testing. But a few worried about confidentiality, especially whether the results could affect their [health insurance coverage](#). A few also expressed fears about getting bad results. As one participant explained, "I mean, you want to know, but then you don't want to know."

- Participants gave several reasons why they decided to undergo testing. Most simply said they were curious. "I don't have a scientific background, so a lot of it is just fascinating to see how all of that can spin out," one participant said.
- Many also said test results would provide knowledge they could act on and help them prepare for the future. Said one: "If you know that there's something going on, you can go ahead and fix it now and not have to try to fix it later when it's already unfixable."
- A few participants wanted to help their families or the next generation, or more broadly, contribute to research and medical science.
- Most participants were pleased with results of the tests, mainly because they had not received bad news, despite the uncertainty of the results. "This makes me feel great," said one such participant. "I know I'll be around at least another year or two."
- About half the participants said they had made no changes in response to results, mainly because there was nothing on which to act. But among a few participants, receiving "low-risk" results was a motivating factor to improve their health behavior, mainly through more exercise and a better diet.
- One year after testing, most participants said they would take the test again and recommend it to others. "It's as if you stepped into a time capsule and you went ahead in time and you can see something," one participant said.

Patients were interviewed individually four times: during an initial session in which a saliva sample was given; four to six weeks later, when they received results; three months after receiving results; and 12 months after receiving results. All interviews were recorded and transcribed

verbatim.

The patients ranged in age from 29 to 63; the average age was 49.5. Sixty percent were female, 50 percent were white and 50 percent were African-American. Thirty percent were high school graduates, 40 percent had some college, 25 percent were college graduates and 5 percent were postgraduates.

Researchers concluded: "This longitudinal, qualitative study adds more in-depth information to the emerging data on participants' decision-making process about, the experience of and reactions to direct-to-consumer testing over time . . . It is possible that our findings could be relevant to more general consumers with similar demographics, though further investigation is needed."

Companies such as 23andMe and Navigenics test consumers' genomes for single-gene disorders, such as cystic fibrosis; for risks of developing complex disorders involving multiple genes, such as cancer, heart disease and diabetes; for sensitivities to drugs such as Coumadin; and for traits such as baldness. Costs range from approximately \$100 to \$1,500. Consumers can order these tests directly and receive results without the involvement of a qualified health-care professional, such as a geneticist or genetic counselor.

Provided by Loyola University Health System

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