

Rational, emotional reasons guide genetic-testing choices

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Consumers decide whether to use mail-in genetic tests based on both rational and emotional reasons, a finding that adds to a growing body of health-care behavior research on information seeking and avoidance, according to researchers at the University of California, Riverside.

In a study of what motivates or discourages consumers from participating in direct-to-consumer (DTC) [genetic testing](#), UC Riverside psychologists found that potential users of the tests were influenced by perceived benefits and barriers to testing, and anticipated regret over testing versus not testing.

"We were interested in examining how people perceive DTC genetic testing and how information about the procedure might influence their interest in testing, not about the advantages or disadvantages of the testing procedure itself," said Kate Sweeny, assistant professor of psychology and lead author of "Predictors of interest in direct-to-consumer genetic testing." The paper appears in the online edition of the peer-reviewed journal [Psychology & Health](#).

"DTC genetic testing provides a context to examine people's decisions to seek or avoid information that could be potentially life-changing, but that only requires a relatively affordable fee to acquire," she explained.

The study provides much-needed evidence to illuminate the processes that drive decisions to pursue or not pursue DTC genetic testing, and reveals how the manipulation of available information substantially

affects perceptions about testing and intentions to test, co-authors Sweeny and graduate student Angela Legg concluded.

With the completion of the U.S. Human Genome Project, which mapped the genes responsible for physical and functional traits, the number of direct-to-consumer genetic tests has exploded. Hundreds of private labs offering the tests provide consumers with information about genetic health factors and ancestry after they return a saliva sample in a mail-from-home kit. The U.S. Food and Drug Administration decided earlier this year to limit the controversial tests on a case-by-case basis.

Sweeny and Angela Legg surveyed 99 volunteers about perceived benefits of genetic testing (increased knowledge of personal and family health risks), perceived barriers to testing (i.e. lack of governmental regulation, the potential misinterpretation of genetic information), anticipated regret over testing or not testing, and intention to pursue the tests.

Volunteers were randomly divided into three groups and presented with different kinds of information – either positive information about DTC genetic testing, negative information, or both positive and negative information.

Participants who received only positive information perceived the greatest benefits of DTC genetic testing, anticipated the greatest regret over missing the opportunity to test, and expressed greater intentions to pursue testing, Sweeny and Legg found. Participants who received only negative information perceived greater barriers to testing, anticipated the greatest regret over testing, and did not differ from people who received both positive and negative information in their intentions to test.

"Our findings have important implications for both predicting and influencing decisions to pursue DTC genetic testing," the researchers

wrote, suggesting that "decisions regarding DTC genetic testing depend on some of the same considerations that drive other health behavior decisions. Numerous studies support the roles of perceived benefits and barriers in decisions to undertake preventative health behaviors and to undergo some types of genetic testing. Although our study is the first we know of to examine the role of anticipated regret in genetic testing decisions, anticipated regret also predicts some preventative health behaviors."

The debate over whether people should undergo genetic testing at all, and particularly DTC genetic testing, is unresolved, the researchers said, noting that critics "express great concern over the lack of counseling following testing, the potential for misinterpretation of test results and the possibility of genetic discrimination. ... We do not attempt to resolve the ethical debate over DTC genetic testing, but our findings suggest that discouraging DTC genetic testing may prove easier than encouraging people to undergo testing."

Sweeny said the research data do not endorse or warn against DTC genetic testing. "Rather, I see our findings as evidence that people who learn about the procedure seem to lean against pursuing it, even when they learn about both pros and cons of testing. I'm not saying that people should or shouldn't test; rather, people in our study seemed particularly attentive to the disadvantages of testing, such that people who learned about both pros and cons were just as (dis)interested as people who only learned about the cons."

One conclusion of the study is that decisions about DTC [genetic testing](#) are similar in some ways to other types of health decisions, for example, that perceptions of costs and benefits of the behavior play a strong role in decision-making, Sweeny said.

"Furthermore, our study adds to a relatively recent trend in research on

health behavior to focus on both beliefs (i.e., the more rational aspects of decision-making) and emotions. We found that both beliefs about DTC testing and anticipated regret about testing decisions were related to intentions to test, suggesting that people are guided by both rational and emotional considerations when they make these decisions."

Provided by University of California - Riverside

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