

How to Motivate People to Get Tested for Inherited Cancer Risk

Remote online genetic education programs can spur testing for inherited susceptibility to cancer, the GENERATE study suggests.

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- In the GENERATE study, 90% of those who viewed an online genetic education program chose to be tested for inherited predisposition to pancreatic cancer
- Participation in the online genetic education program did not increase participants' concerns about developing cancer

Even as it's become clear that an inherited susceptibility to some cancers is more common than once thought, genetic testing of family members of cancer patients hasn't increased as much as experts had hoped. A new study led by researchers at Dana-Farber Cancer Institute and Brigham and Women's Hospital demonstrates that a remote online genetic education program can be a powerful motivator for people with a family history of cancer to undertake genetic testing.

The GENetic Education, Risk Assessment, and TEsting (GENERATE) study included 601 people from across 45 states who had a close relative with the most common form of pancreatic cancer. Participants received genetic education through one of two remote online programs. After participating in one of the two genetic education interventions, 90% of the participants completed testing for inherited variations in more than a dozen genes linked to pancreatic cancer.

The impressive response to the remote genetic education programs was bolstered by participants' reactions to being tested. The 400 participants who completed a questionnaire on their experience indicated that testing did not spark anxiety, depression or worries about cancer after receiving their genetic testing results.

"We know that 5 to 10 percent of all cancers are linked to inherited genetic variations. We know the specific variants linked to those cancers. And we know that cancer incidence and mortality can be reduced by identifying people who carry those variants and intervening to lower their cancer risk or closely monitor them to detect cancer at its earliest stages when it is most treatable," says study senior author [Sapna Syngal, MD, MPH](#), Co-Director of the Centers for Early Detection and

Interception at Dana-Farber Cancer Institute and a faculty member at Brigham and Women's Hospital. "But we also know that not enough people who could benefit from genetic testing are being tested."

Among the potential barriers to testing are a limited public understanding of inherited cancer risk, lack of communication between an individual with cancer and family members who may be at risk for it, out-of-pocket costs, and a lack of nearby testing services and genetic counselors.

"We need new methods to make testing more available and increase awareness of its benefits," Syngal remarks. "The goal of this study was to assess how remote genetic education programs that people could access at home, online, might impact the decision to have genetic testing."

The study was open to people 18 years or older who had a first-degree relative with pancreatic ductal adenocarcinoma (PDAC) or a first- or second-degree relative with PDAC and an inherited variation in any of 13 genes linked to the disease. Participants were recruited through social media advertisements, pancreatic cancer advocacy organizations, and the six institutions collaborating on the GENERATE study.

The 601 participants, representing 424 families, were randomly assigned to one of two groups. One group participated in an interactive genetic education video session and viewed a seven-minute genetic education program narrated by a cancer physician. The other group had access only to an online genetic education program through a commercial laboratory website. Both groups had access to all materials in the online genetic education program available through the commercial laboratory website.

After completing the program, 541 participants, representing 90% of the entire study group, elected to undergo testing for inherited variations in PDAC-linked genes – opting to receive a saliva-based genetic testing kit shipped to their homes that they would then use to send a sample by mail to a testing center.

One of the most encouraging aspects of the study is the geographic range of the participants, researchers said. More than half of all those who enrolled in the study were not family members of patients at the six study sites, suggesting they heard about the study through social media or advocacy organizations.

"This demonstrates that online education is a real option for people who may not live near a genetic counseling center or testing facility," says the study's first author, Nicolette Juliana Rodriguez, MD, MPH, of Dana-Farber and Brigham and Women's Hospital.

All participants completed surveys of their psychological well-being – including feelings of anxiety, depression and cancer worry – when they enrolled in the study, followed by questionnaires when they completed the program and three months later. Among the 400 who completed the questionnaires, the remote genetic education and testing programs had no impact on their anxiety, depression or cancer worry.

“Our findings demonstrate that remote healthcare delivery methods have broad reach, are a successful and complementary option to traditional in-person models, and can increase the use of genetic testing,” Rodriguez remarks. “It’s critical that we continue to develop strategies of care delivery for historically marginalized racial and ethnic communities to ensure they have equal access to cancer genetics services.”

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