When it comes to home cancer tests, think before you spit

This image provided by 23andMe shows the company's logo.(Photo: Anonymous, AP)

U.S. consumers soon will be able to test themselves at home for some genetic mutations that increase the risk of breast, ovarian and prostate cancer — but you might want to think before you spit.

Genetic counselors, cancer doctors and other experts are urging consumers to do their homework before they send in saliva samples and allow their DNA to be screened for certain cancer risks by the company 23andMe.

“We’ve got some work to do to help people know what they are getting into,” with the first approved home tests for genetic cancer risks – and the additional tests that are likely to follow, said Robert Cook-Deegan, a professor in the School for the Future of Innovation in Society at Arizona State University.

First, the basics of the new test, approved by the Food and Drug Administration Tuesday:

• 23andMe, which already offers $199 tests on ancestry and some health risks, will be able to tell users whether they carry three mutations of genes known as BRCA1 and BRCA2. Women who carry any of these mutations have a 45% to 85% breast cancer risk. The mutations also are associated with increased risks of ovarian and prostate cancers.

• This test is mostly of use to people of Ashkenazi Jewish descent. About 2% of Ashkenazi Jewish women have one of the mutations, but they occur very rarely in other ethnic groups, the FDA says.

• A negative result will not rule out any cancer risk – by a long shot. That’s because the test covers just three out of more than 1,000 known BRCA mutations and none of the other genetic, environmental or lifestyle factors that might increase risks.

“Most BRCA mutations that increase an individual’s risk are not detected by this test,” the FDA’s Donald St. Pierre said in a press release full of cautions and caveats.

In a blog post, the American Cancer Society’s chief medical officer, J. Leonard Lichtenfeld, said people with strong family histories of cancer could be misled by apparently reassuring results on such a limited test: “In short, you might be led to think you are off the hook, when the hook is still very much intact.”

The FDA and 23andMe also said that consumers who take the tests should not use the results to make medical decisions – like how often to have mammograms – without consulting medical providers.

But in a perfect world, a discussion with a medical provider would still happen first, before someone decides whether to get tested and which tests to take, said Susan Domchek, an oncologist who directs the Basser Center for BRCA at the University of Pennsylvania.

“You need to be tested for the right thing,” and that will not necessarily be the mutations on the new test or future home tests, she said. “I think genetic testing is best used in the context of all of your ongoing medical care.”

No one should take such a test on a whim, said Mary Freivogel, a certified genetic counselor in Denver and past president of the National Society of Genetic Counselors.

“One thing I want people to think about is how prepared you are for this information,” she said. “You test positive for this, and all of the sudden you have this set of heavy decisions on your lap.”

Also, she said, “You have to think about family dynamics,” among relatives who share your genes. “You have to be prepared to share this information with your family... including the sister you haven’t talked to in ten years.”

A genetic counselor can help people sort through such possibilities before testing, she said.

Despite the possible pitfalls, home genetic testing is likely to grow and many people will not get counseling first, experts concede. That means consumers need to get better informed, said Robert Green, a medical geneticist at Brigham and Women's Hospital, Boston.

“In a world where people are more and more asking to see their own data, whether that’s their fitness data or their blood pressure,” or genetic profiles, “there is a responsibility on the part of the consumer to really think about what they are getting and take responsibility for understanding it,” he said.

Green has conducted studies that suggest consumers can understand such testing and make appropriate use of the results.

But some people will, inevitably, be blindsided by upsetting results and have to pick up the pieces with their doctors and families, Cook-Deegan said. Overall, greater access to the information is “a good thing,” he said, but dealing with the fallout “is just something we will have to get used to, as a culture.”

23andMe offered BRCA testing without FDA approval several years ago, but the FDA ordered it to stop in 2013 until it could prove that test and other health tests it offered were accurate and adequately explained to consumers. The FDA has since allowed the company to test for a few genetic mutations linked to health risks, including some for Alzheimer's and Parkinson's. Tuesday's approval was the first for genes linked to cancer.