

The New York Times

New Gene Tests Pose a Threat to Insurers

By [GINA KOLATA](#) MAY 12, 2017



Pat Reilly, 77, at home in Ann Arbor, Mich., last week. Ms. Reilly found that she had inherited an ApoE4 gene that increases the risk of developing Alzheimer's disease, and bought a long-term care policy in response. Credit Laura McDermott for The New York Times

Pat Reilly had good reason to worry about Alzheimer's disease: Her mother had it, and she saw firsthand the havoc it could wreak on a family, much of it financial.

So Ms. Reilly, 77, a retired social worker in Ann Arbor, Mich., applied for a long-term care insurance policy. Wary of enrolling people at risk for [dementia](#), the insurance company tested her memory three times before issuing the policy.

But Ms. Reilly knew something the insurer did not: She has inherited the ApoE4 gene, which increases the lifetime risk of developing Alzheimer's. "I decided I'd best get long-term care insurance," she said.

An estimated 5.5 million people in the United States have Alzheimer's disease, and these patients constitute half of all nursing home residents. Yet very few people in the United States have been tested for the ApoE4 gene.

But [last month, with the approval](#) of the Food and Drug Administration, the gene testing company 23andMe began offering tests that reveal whether people have the variant, as well as assessing their risks for developing such conditions as Parkinson's and [celiac disease](#).

Other [genetics](#) companies are planning to offer similar tests, and soon millions of people will have a better idea what their medical futures might be. Recent research has found that many, like Ms. Reilly, are likely to begin preparing for the worst.

But for companies selling long-term care insurance, these tests could be a disaster, sending risky patients in search of policies even as those with fewer risks shy away, damaging an already fragile business. “There is a question about whether the industry is in a death spiral anyway,” said Robert Hunter, director of insurance at the Consumer Federation of America. “This could make it worse.”

The tests are simple: All people have to do is send away a saliva sample and pay \$199. Their disease risks, if they say they want to know them, will be delivered with a report on ancestry and on how their genes influence such traits as flushing when they drink alcohol or having straight hair.

The company will not reveal how many people have received disease-risk data, but it says that in Britain and Canada, where it has offered such testing for several years, about three-quarters of their customers have asked for it. 23andMe has sold its genetic services to more than two million people worldwide since 2007.

Under the Genetic Information Nondiscrimination Privacy Act, companies cannot ask employees to take gene tests and cannot use any such results in employment decisions; insurers are not permitted to require gene tests or to use the results in coverage decisions.

But legislation proposed in the House would exempt corporate “wellness” programs from some of these requirements. And the American Health Care Act, passed by the House, would permit states to waive some insurance safeguards regarding pre-existing conditions.

At the moment, companies selling long-term care insurance — unlike medical insurers — are permitted to ask about health status and take future health into consideration when deciding whom to insure and how much to charge.

The 23andMe test results will not appear in people’s medical records, and the company promises not to disclose identifiable findings to third parties. It is up to the customers to reveal them — and the fear for insurers is that many will not.

Two-thirds of nursing home residents are on [Medicaid](#), and the remaining private insurers are already struggling. In the early 2000s, more than 100 firms [offered long-term care insurance](#), according to the Treasury Department. By the end of 2015, only 12 firms offered it, and new enrollees fell from 171,000 to 104,000.

The insurers charged too little for these policies, experts say; policyholders have turned out to be much sicker than anticipated. To pay for an unanticipated increase in policyholders who develop Alzheimer’s, insurers would have to raise prices, said Don Taylor, a professor of public policy at Duke University who has [studied](#) the issue.

Increasing numbers of people at low risk might decide the insurance was not worth the rising price. Even many at high risk would eventually find the policies unaffordable. It is the definition of an insurance death spiral.

If that happens, said Mark Rothstein, the director of the bioethics institute at the University of Louisville's medical school, even more people with Alzheimer's will end up on Medicaid, with the federal government paying for their nursing home care.

Someone must pay, he said. The only question is whether it will be taxpayers or policyholders. "How do you want to spread the risk?" Mr. Rothstein asked.

For 23andMe, the new tests are simply a way to help people learn about their makeup. "People clearly want information about themselves," said Anne Wojcicki, the chief executive at 23andMe. "There is a demand."

Yet even if just a minority of 23andMe customers decided to game the current insurance system, "it's enough to perturb the market," said Dr. Robert Cook-Deegan, a professor at the school for the future of innovation in society at Arizona State University, who has studied the issue.

[Research](#) by Dr. Robert C. Green, a geneticist at Harvard University, indicates that this is exactly what is likely to happen. Drawing on data from his clinical trials involving more than 1,000 people, Dr. Green has found that people who learn they have the ApoE4 gene fare just as well if they get the results without counseling.

But he also found that those who learned they had the gene variant — Ms. Reilly was one of them — were nearly six times more likely to buy long-term care insurance than those who did not. The ApoE4 gene variant is present in about a quarter of the population.

Many thought there was no need to tell the insurer why they suddenly wanted a policy. "All the insurance companies are concerned about this," said Dr. Green, who has been discussing the problem with industry executives.

Major insurers declined to comment. A trade group, American Council of Life Insurers, issued an email statement by Mariana Gomez-Vock, the group's senior counsel.

"Though it is difficult to speculate on the potential impact of the latest 23andMe offering, any situation that has the ability to significantly increase adverse selection could impact the availability and affordability of products over time," she wrote. "We need to be on the same page with the applicant, where both sides share the same information," she added.

But will that happen? "I don't see a good outcome here," Mr. Taylor said.