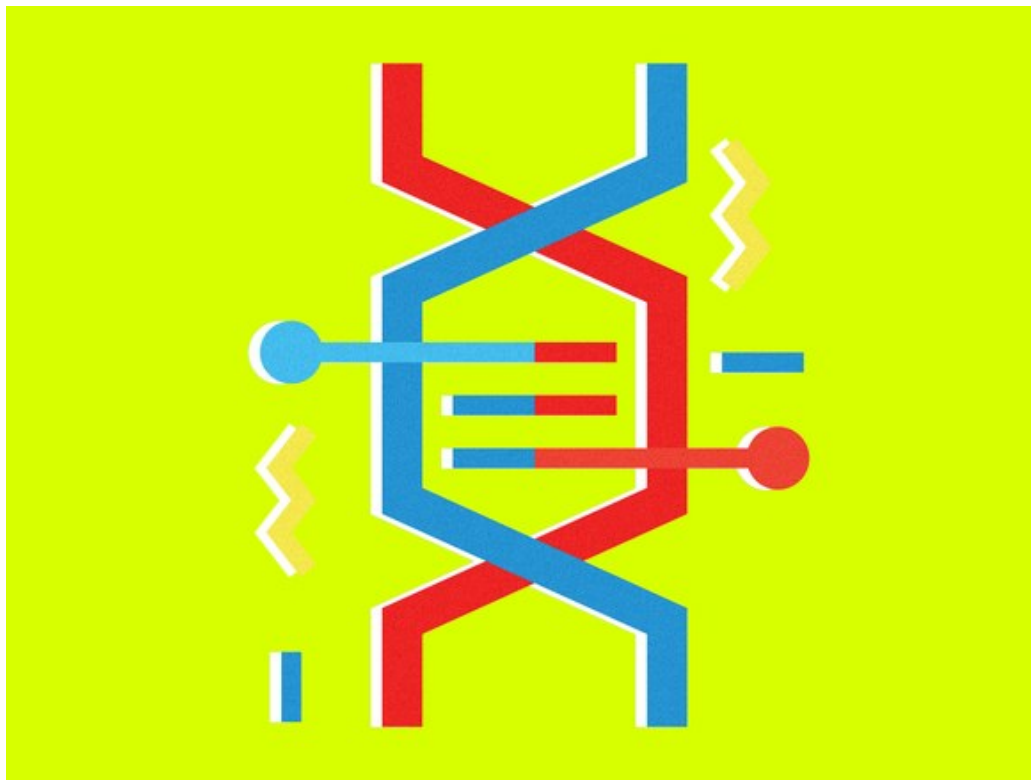


ADAM ROGERS SCIENCE 05.04.17 07:55 PM

# THE HOUSE HEALTH PLAN MAKES YOUR GENES A PREEXISTING CONDITION



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OF ALL THE provisions of the Affordable Care Act—“Obamacare,” if you’re on a

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something and lost your insurance, or if you quit or got fired, you could still get onto a plan.

But the odds say that sick people stay sick or get sicker, and insurance companies don't make a profit by paying out. By voting to repeal the ACA and replace it with ... well, with something, not totally clear what, the Republican-led House of Representatives seems to have nuked the preexisting condition guarantee. The new bill, which passed in a close 217-213 vote, allows insurance companies to charge sick people more. According to one nonpartisan analysis, it allocates enough money to cover those higher rates for just 5 percent of people with preexisting conditions.

Think it can't get worse? Hold, as the saying goes, my beer. The ACA *specifically* protected against discrimination for preexisting conditions that showed up through genetic tests. You might not be sick yet—in technical terms, the illness has not manifested—but if you, for example, test positive for one of the pathogenic variants (a less X-Manly term than “mutation”) in the BRCA gene that predisposes you to breast cancer, you could still get covered. If the House bill becomes law, that protection vanishes.

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helped scientists better define a preexisting genetic condition. The more you know about genetics, the more conditions start to look preexisting. But multiple interacting genes and environmental effects mean it's hard to tell what'll turn from potential to real. The issue is "penetrance"—what proportion of people who have a pathogenic variant will actually get the disease? "You could say all of us have a preexisting condition of import, and it's just a matter of when we're going to manifest it," says [Eric Topol](#), a genomicist at the Scripps Research Institute. "Very few of us are genetically bulletproof."

It's not like nobody saw this debate coming. Even back when sequencing a human genome cost \$100 million, policymakers and scientists were trying to figure out how to safely get data from people while simultaneously keeping insurers and employers from using it to screw them. After a decade of debate, the result was the [Genetic Information Nondiscrimination Act](#), a 2008 bill that aimed to protect people's genetic privacy. GINA wasn't perfect—it doesn't extend to long-term care and life insurance, for example.

GINA also doesn't quite define illness. It protects family history and tests of DNA, RNA, proteins, metabolites, and other indicators—a panoply of -omics beyond just genomics. But it doesn't protect you if you already have symptoms. So then the question is, what counts as a symptom? Is a person only sick when they first start feeling pain? When a doctor prescribes a drug? Or when something changes on a cellular level? "When you don't have symptoms and you aren't disabled or have some other significant clinical syndrome, does that mean that it's preexisting? When it's encoded in your DNA or other parts of your intrinsic self?" Topol asks.

In other words, when does "preexisting" turn to "existing?" More sophisticated, more widely available, and less expensive tests make that area greyer and greyer. An example: Let's say you have a pathogenic variant in a Long QT gene, associated with sudden cardiac death. ([Three main genes](#) account for three quarters of cases.) "GINA would protect against employers and health care from discriminating against you on the basis of that genetic finding, but once you got

predisposition and manifestation. If you take away Obamacare, you open this vast grey area again.”

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That same issue comes up with every biochemical variation of clinical significance. Find it via sequencing? Covered. Find it via a blood test? You're out. "It just makes it messier and more unclear, because of the overlap between manifestation and genetic testing," says Anya Prince, a lawyer and researcher at the Center for Genomics and Society at UNC. "The law always has difficulty in

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couple years after GINA, nobody ever really had to find out what GINA will actually protect. “These definitions haven’t been fully tested because they haven’t shown up in court,” Prince says. Just an example: Fiscal 2013 saw 333 employment discrimination complaints based on GINA ... and 90,000 based on everything else—mostly the Americans With Disabilities Act. Most people have never even heard of GINA. If Congress and the President replace Obamacare with something like what the House has cooked up, that’ll change, because GINA will be the only way to force insurance companies to cover people with preexisting conditions.

Unless, listen, you might as well just drink that beer at this point, because in early March a House committee passed HR 1313, which says that GINA doesn’t apply to workplace wellness programs. If the bill passes, or becomes part of a bigger bill, employers could ask for genetic information under the guise of creating healthier environments. But since employers are the ones who carry insurance, they could also just fire people who pop a bad test.

Despite how grim all this sounds, it might turn out OK. Genetics isn’t destiny. “Insurance companies don’t know how to deal with this, because there aren’t good metrics to put into their underwriting algorithms,” Green says. So maybe people don’t actually need to firewall their genetic information. Insurers won’t be able to do anything with it today, because nobody understands it well enough. And then, maybe in years or decades, genetic tests will actually lead to better health outcomes. That’d be a win for insurers and the insured.

Unless, of course, people don’t participate in the studies. Green has been working on the kind of research that might someday turn into those win-win outcomes—like, for example, his lab’s work sequencing the genomes of a bunch of newborn babies. When his team went to sign people up, they got a 10 percent recruitment rate—to get 300 families they had to ask 3,000. “There are a lot of reasons,” says Green, “but about the third most common was concerns about privacy and discrimination.” If people feel afraid to be part of the data-gathering effort, it’ll inhibit those blue-sky results. The policy will have failed

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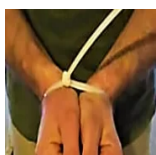
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