

STAT

Opposition grows to ‘workplace wellness’ bill that would scale back genetic privacy

By [Sharon Begley @sxbegle](#)

March 13, 2017



Damien Meyer/AFP/Getty Images

Opposition to a congressional bill that would explicitly remove genetic privacy protections from workplace wellness programs grew on Monday, with one of the country’s leading wellness associations calling the proposed changes “punitive.”

The bill, approved by a House committee last week, [would eliminate long-standing genetic privacy protections](#)¹ from workplace wellness programs, which are allowed to charge thousands of dollars more in premiums, deductibles, and copayments to employees who do not participate. If passed by the full House and Senate and signed by President Trump, the bill would free employers’ wellness programs from the existing constraints of the landmark Genetic Information Nondiscrimination Act.

Although the legislation was championed by some business groups, the Wellness Council of America said Monday that it would oppose the bill.

Allowing employers to require employees to undergo genetic testing and to turn over the results to companies running wellness programs could cause “harm both mentally and physically to employees,” said Ryan Picarella, CEO of the the group, known as WELCOA, a trade association of some 6,000 companies that sell wellness programs to employers and of employers that offer them to workers.

[Related:](#) ¹

[House Republicans would let employers demand workers' genetic test results](#) ¹

When employees feel they are being coerced into a wellness program, Picarella said, it can create a “toxic environment” that raises stress levels, which have been linked to a higher rate of cardiovascular disease, cancer, depression, and other illnesses.

WELCOA signed onto a statement from a new group consisting of trade associations, wellness companies, and other businesses, called Ethical Wellness, that announced its opposition to the bill. “We find the collection of genetic information on employees to be inconsistent with” the group’s code of conduct, it said. In addition to violating employee privacy, the group said, the bill provides “too much opportunity for such data to be misused or misinterpreted.”

Ethical Wellness also disputed the claim, which dates to the Obama administration, that wellness programs that make workers pay 30 percent, and possibly 50 percent, more for health coverage are “voluntary.” The programs typically include blood and other biometric testing; questionnaires asking workers what they eat, whether they’re ever depressed, whether they plan to get pregnant; and sometimes smoking-cessation and weight-loss programs.

“Employees facing forfeitures of thousands of dollars for non-compliance will find such a demand [to participate in wellness programs] to be financially coercive,” the group said, adding that it “urge[s] Congress to reject this misguided legislation on multiple grounds.”

On NBC’s “Meet the Press,” Tom Price, secretary of Health and Human Services [said](#) ² over the weekend that the Trump administration might have “significant concerns” about the bill.

Leading geneticists raised alarms about how employers might use employees’ genetic information.

Genetic testing labs are largely unregulated. Although they have to adhere to good laboratory practices in how they handle DNA samples, there is almost no quality check on how they interpret the genetic variants they identify. As a result, one testing lab may call a variant “pathogenic,” or likely to cause disease, while another will call it “benign.”

In one [quality test](#) ⁵, researchers gave genetic variants related to nine common conditions to nine labs. The labs disagreed 22 percent of the time, meaning one thought a genetic variant was a problem and another did not, said geneticist Heidi Rehm of Brigham and Women’s Hospital, who helped lead the

study.

“It’s not the case that every lab interprets genetic variants the same,” said Rehm. Only one interpretation is right. That means that an employee persuaded to undergo genetic testing by an employer runs the risk of being given incorrect information, even that her BRCA1 gene puts her at risk for breast and ovarian cancer when it does not. Workplace wellness programs are not required to use or provide genetic counselors to vet the lab results or help employees understand them.

And because medical genetics remains an imprecise science, “even if everyone agrees that a genetic variant can cause disease, the actual risk to an individual of developing that disease is not that clear,” Rehm said. “That risk depends on environmental factors as well as other genetic ones, but truthfully we don’t know what those factors are,” let alone how much they change a person’s risk of disease.

Rehm and other scientists whose research involves finding ways to use people’s genetic profiles to improve their health are deeply concerned that the House bill would set back those efforts.

When pioneering projects like [MedSeq](#)⁶ and [BabySeq](#)⁷ ask people if they would be willing to participate, a common reason they decline is fear of genetic discrimination, said medical geneticist Dr. Robert Green of Brigham and Women’s, who helps lead both studies.

“We explain that we would put the results of genetic testing into their medical record so their physicians can draw on it,” Green said. “We explain that GINA covers [and bars discrimination in] health insurance. That has worked to partly reassure people.”

[Related:](#) ²

[HHS secretary expresses concern on bill allowing employers to demand genetic tests](#) ²

But if employers are allowed to ask employees to share their genetic results, as the House bill would permit, or pay upward of \$6,000 more for health care coverage, that reassurance would be false. “It’s a disaster for research,” Green said. “I’m tearing my hair out. Who wants to reveal to their employer that they have a BRCA mutation? It would just incentivize employers to get rid of people at risk for future, expensive illnesses.”

That concern was reportedly shared by scientists developing a [study](#)⁸ at the National Institutes of Health that, starting this year, would collect genetic and other information on 1 million or more Americans. Volunteers would be assured that their genetic information would be private, but under the House bill that could not be guaranteed. The NIH did not immediately reply to a request for comment.

“GINA was passed so you can participate in genetic research without your employer or insurer asking you for the information,” said Derek Scholes, director of science policy at the American Society of Human Genetics, which opposes the bill. The NIH study “says people will get back [genetic and other] information which is useful to their health. If this bill goes through your employer can say, ‘give us that

information” or else pay thousands of dollars more for health insurance and health care.

Supporters of the bill insist that this financial consequence does not make a workplace wellness program involuntary, and that it addresses employers’ confusion about what is and isn’t allowed.

About the Author



[Sharon Begley](#)⁹

Senior Writer, Science and Discovery

Sharon covers science and discovery.

sharon.begley@statnews.com¹⁰

[@sxbegle](#)¹¹

Tags

Links

1. <https://www.statnews.com/2017/03/10/workplace-wellness-genetic-testing/>
2. <https://www.statnews.com/2017/03/13/price-employers-genetic-information/>
3. <https://www.statnews.com/signup/>
4. <https://www.statnews.com/privacy/>
5. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3763716/>
6. <http://www.genomes2people.org/the-medseq-project/>
7. <http://www.genomes2people.org/babyseqproject/>
8. <https://www.nih.gov/research-training/allofus-research-program>
9. <https://www.statnews.com/staff/sharon-begley/>
10. <https://www.statnews.com/2017/03/13/genetic-privacy-wellness/mailto:sharon.begley@statnews.com>
11. <https://twitter.com/sxbegle>
12. <https://www.statnews.com/tag/congress/>
13. <https://www.statnews.com/tag/policy/>
14. <https://www.statnews.com/tag/precision-medicine/>
15. <https://www.statnews.com/tag/wellness/>

© 2018 STAT