Preserving Employee Wellness Programs Act (HR 1313, 115th Congress)

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The Policy

What it does
Expands the ability of workplace wellness programs to collect personalized genetic information from employees but still remain in compliance with the Genetic Information Nondiscrimination Act, the American Disabilities Act, and the Public Health Service Act.

Synopsis

HR 1313 aims to clarify and simplify the rules governing workplace wellness programs by US employers, so as to streamline their implementation. The bill’s goal is to reduce the legislative and regulatory burdens that restrict the extent to which employers can implement these programs, which are proposed to both drive down health costs and improve employee health. The legislation would grant employers increased access to employee health data.

In essence, the bill would allow employers broader authority to collect identifiable personal and familial medical history and genetic tests through voluntary wellness programs. These programs can offer a limited reward to enlist employees, such as a discount on employer-sponsored health plan premiums. Previous litigation has debated whether such incentivized programs could be deemed “voluntary”—this bill would solidify that they are.

The bill concerns wellness programs that meet the following broad requirements:

- If offered in conjunction with an employer-sponsored health plan, meet the definitions and conditions governing wellness, disease prevention, and health promotion programs outlined in 42 U.S.C. 300gg-4(j);
- Comply with any regulations promulgated by the Department of Labor, the Department of Health and Human Services (HHS), and the Department of the Treasury;
- Provide rewards of no more than 30% of the total cost of an employer-sponsored health plan (although the DOL, HHS, or Treasury can increase the reward to 50%).

In addition, this bill also concerns programs that offer more favorable treatment for individuals with adverse health factors, as set out in 45 CFR 146.121(g).
Programs meeting these requirements will be considered exempt from further wellness program-related restrictions promulgated by the American Disabilities Act of 1990 (ADA) \[42 U.S.C. 12112(d)(4)(B)\] \[21\], the Public Health Service Act (PHS Act) \[42 U.S.C. 300gg-4(d)\] \[16\], and the Genetic Information Nondiscrimination Act of 2008 (GINA) \[42 U.S.C. 2000ff-1(b)(2)\]. \[22\] Several notable clarifications and changes in the governance of wellness programs include:

- Employers asking for medical histories and health appraisals, even in relation to disabilities, would be considered in compliance with ‘acceptable examinations and inquiries’ as outlined in the ADA. This solidifies an Equal Employment Opportunity Commission (EEOC) ruling \[23\] that the incentive provided by the ‘reward’, whether financial or in-kind, is not sufficient to render an employee’s decision to participate as involuntary. Essentially, it would clarify that employee participation is, in fact, voluntary, so as to limit litigation around the subject.
- Any activity of wellness programs, including genetic testing and inquiring about family history, would be considered in compliance with the PHSA and ADA exemptions for ‘underwriting purposes’, those used to determine eligibility for or the cost of a health plan.
- Employers would be able to collect personal genetic information, whereas currently they can only access genetic information in a de-identified, aggregate form. This is already problematic at small companies where it is simple to identify employees with limited genetic information.
- Employers would be able to collect information about the manifested disease or disorder of a family member (a dependent or a relative up to the fourth degree) without violating GINA.

Further, the bill empowers administrative agency influence by shifting the authority of regulatory interpretation from the independent EEOC to the HHS, DOL, and the Treasury.

**Context**

Concerns over discrimination based on genetic information have existed for several decades now, but finally became a reality when research into genetics picked up pace at the beginning of the 21st century. In 2000, President Bill Clinton issued Executive Order 13145 \[24\], which barred discrimination in the Federal government on the basis of genetic information. First proposed in 2003, GINA was passed with near-unanimous support in 2008 and effectively extended this prohibition to employers and health insurance issuers.

In 2010, President Barack Obama signed the Patient Protection and Affordable Care Act (ACA) into law, which largely incentivized employers to implement workplace wellness programs. It allowed them to give participating employees rewards, such as rebates or discounts on premiums, valued at up to 30% of the cost of health plan coverage. Under provisions laid out in GINA and ACA, employers who set up workplace wellness programs could coerce their employees to choose between participating and not receiving the subsidies.

All of this laid the groundwork for President Obama’s Precision Medicine Initiative \[25\], which has now evolved into the National Institute of Health’s All of Us Research Program \[26\]. All of Us aims to pool genetic information from millions of Americans by 2019, in hopes of aggregating enough information to detect genetic variants of use to medical interventions.

**Policy History**

An earlier version of this bill was introduced in 2015 as HR 1189 \[27\] (114th Congress), though by a different sponsor, Representative John Kline \[28\] (R-MN-2). The text of the bill is different, but the content is essentially the same.

**The Science**

**Science Synopsis**

Workplace wellness programs \[13\], as defined by PHS Act \[29\], are programs established by employers with the goal of health promotion or disease prevention. Many of these programs target “lifestyle diseases” \[30\] that are brought on by unhealthy daily activities or environments, such as smoking, drinking, poor diet, and lack of exercise. These programs aim to curb these diseases as well as enhance preventative measures for other chronic or genetic diseases by incentivizing participation in health-related activities, like the following:

- Smoking cessation programs;
- On-site fitness centers;
- Weight management programs;
- Medical screenings and health risk appraisals \[31\];
- Diagnostic tests, including direct-to-consumer genetic tests \[32\];
- Health education and coaching;
- Preventive care \[33\]; and
- Other lifestyle modification programs, such as those aimed at lowering cholesterol or blood pressure.

While these programs enjoy bipartisan support politically as well as general support amongst employers and employees alike, there is limited evidence \[34\] demonstrating that they lower costs or that they improve health outcomes for employees. Studies about the efficacy of wellness programs are often criticized \[35\] for weak methodology and only considering short-term impacts, and many are funded by the workplace wellness industry itself, presenting a potential conflict of interest. No general conclusions about their efficacy have been drawn by the scientific community at this time.

One of the more controversial aspects of workplace wellness programs is the collection of genetic information \[36\], which is essentially the results of an individual’s or family member’s genetic tests \[37\] or evidence of a genetic disease or disorder of a family member. These tests, as defined by GINA \[38\], cover a vast number of techniques that analyze human DNA, RNA, chromosomes, proteins, or metabolites, to detect an individual’s genetic makeup (genotypes, mutations, or chromosomal changes). They are often used in health care to assess genetic risk factors and potentially mitigate the harms associated with genetic diseases \[39\], sometimes before they even emerge.

In the context of wellness programs, genetic tests can help ensure that employees have the necessary working knowledge to increase preventive care \[33\] or avoid certain behaviors associated with higher risk to certain diseases. For example, a person whose genetic history shows a hereditary risk for skin cancer might take efforts to avoid exposure to the sun or be more inclined to apply sunscreen. This could both reduce healthcare costs as well as increase employee health by staving off
costly and deleterious disease.

A long-term future benefit of genetic information lies in the potential of **precision medicine**. [40] This emerging approach to medicine seeks to incorporate information about an individual’s genes, lifestyle, and environment to create ‘personalized’ medical interventions, as opposed to the general approaches that are thought of as ‘one-size-fits-all.’ Genetic information also might allow researchers to predict how effective an intervention would be based on a patient’s specific genetic variants. Extensive health data collection and sharing will be critical for the development of precision medicine, as researchers need to be able to compare data (genetic and otherwise) from a lot of people, both sick and healthy, to identify the important factors contributing to both disease and health (see the **All of Us Research Program** [41]).

While genetic tests and their potential medical benefits have expanded greatly in recent years, so has their potential for misuse. Broadening employer access to employee genetic information increases the opportunity (and perhaps likelihood) for discrimination, whether implicit or explicit. Furthermore, privacy fears could cause employees to balk at undergoing genetic tests, which could negatively impact individual health as well as the development of precision medicine. Meanwhile, there remains little commentary on how exactly allowing employers to access this information makes wellness program implementation easier or more effective.

**Relevant Experts**

*Misha Angrist, PhD* [42] is Associate Professor of the Practice at SSRI and a Senior Fellow in Science & Society. He serves as the lead of the Public Impact & Engagement track for the MA in Bioethics & Science Policy and as a faculty mentor, and he teaches several MA electives.

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**The Debate**

**Endorsements & Opposition**

**Endorsements**

- The bill’s sponsor, Rep. Virginia Foxx released a [fact sheet] [43] that claims the bill will:
  - Protect wellness programs by eliminating red tape
  - Reassert congressional intent that was inhibited by EEOC investigation and rulings.
  - Encourage lower health care costs for employers, employees, and insurance companies by encouraging healthy behavior and preventive care.
- The American Benefits Council [testified] [44] at a congressional hearing that “the inconsistent federal regulatory framework under HIPAA, GINA, and the ADA has caused many employers to take a step back or pause in their implementation of innovative wellness programs.” They also had previously sent a [letter] [45] of support for an earlier version of the Preserving Employee Wellness Programs Act ([HR 1189](https://scipol.duke.edu/track/hr-1313-preserving-employee-wellness-programs-act), 114th Congress).
- The ERISA Industry Committee issued a [letter] [46] in support of HR 1313, claiming the bill “will untangle conflicting, burdensome, and unnecessary rules that are currently jeopardizing the ability of employers to offer quality wellness programs, and the opportunity for employees to earn significant savings on their health insurance premiums while also improving their health.”

**Opposition**

- The American Society for Genetics released a [statement] [47] urging the committee to not move forward with this bill. “As longtime advocates of genetic privacy, we instead encourage the Committee to pursue ways to foster workplace wellness and employee health without infringing upon the civil rights afforded by ADA and GINA.”
- In a [group letter] [48] to Rep. Foxx, over 70 advocacy organizations, including the AARP, the American Diabetes Association, the American Academy of Pediatrics, the Epilepsy Foundation, and the March of Dimes, opposed the bill claiming genetic information is “unrelated to [employees’] ability to do their jobs” and “imposes draconian penalties on employees who choose to keep this information private.”

**Status**

*HR 1313* was introduced in the House on March 2, 2017, and referred to the [House Committee on Energy and Commerce](https://scipol.duke.edu/track/hr-1313-preserving-employee-wellness-programs-act) [49], the [House Committee on Ways and Means](https://scipol.duke.edu/track/hr-1313-preserving-employee-wellness-programs-act) [50], as well as the [House Committee on Education and the Workforce](https://scipol.duke.edu/track/hr-1313-preserving-employee-wellness-programs-act) [51]. It was also referred to the [Subcommittee on Health](https://scipol.duke.edu/track/hr-1313-preserving-employee-wellness-programs-act) [52].

**Recommended Citation**


**Related Tags**

*Genetic Information Nondiscrimination Act (GINA)* [54] workplace wellness program[55]