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

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[12] aims to clarify and simplify the rules governing workplace wellness programs[13] by US employers, so as to streamline their implementation. The bill’s goal is to reduce the legislative and regulatory burdens[14] 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 its 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[15] 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 workplace wellness programs[13] by US employers, as outlined in the Public Health Service Act (codified in 42 U.S.C. 300gg-4(j)[16]);
- Comply with any regulations promulgated by the Department of Labor[17] (DOL), the Department of Health and Human Services[18] (HHS), and the Department of the Treasury[19]; and
- 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(p)[20].
In the context of wellness programs, genetic tests can help ensure that employees have the necessary working knowledge to increase awareness about genetic diseases and disorders. Genetic tests, such as direct-to-consumer genetic tests, are programs established by employers with the goal of health promotion or disease prevention. These programs aim to target "lifestyle diseases" 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;
- Diagnostic tests, including direct-to-consumer genetic tests;
- Health education and coaching;
- Preventive care; 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 demonstrating that they lower costs or that they improve health outcomes for employees. Studies about the efficacy of wellness programs are often criticized 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, which is essentially the results of an individual's or family member's genetic tests or evidence of a genetic disease or disorder of a family member. These tests, as defined by GINA, 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, 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 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 potential health issues.
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.

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 healthcare 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 [27], 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 [49], the House Committee on Ways and Means [50], as well as the House Committee on Education and the Workforce. [51] It was also referred to the Subcommittee on Health [52].

Recommended Citation


Related Tags

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