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PERSPECTIVE

GINA and ADA: New Rule Seriously Dents Previous Protections

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The Centers for Disease Control (CDC) cites chronic diseases such as depression and hypertension as being among the most common and costly of health problems affecting the workforce. Not only do these diseases contribute to a decrease in the physical and emotional well-being of employees, but they also contribute to lower productivity in the workplace and an increase in missed work days. This can ultimately lead to increase in operating expenses for large businesses, which may then have to issue disability benefits or hire replacements for employees on leave.

Businesses have discovered that much like routine healthcare visits can prevent future serious health conditions, promoting healthy behaviors such as exercise regimens or a healthy diet can decrease the need for more serious medical intervention down the line. Many employers now offer corporate wellness programs designed to support healthy behaviors for employees both at work and at home. They can include allowing time during the work day to exercise, providing areas in the workplace to exercise or eat, and offering health-conscious options in workplace cafeterias or vending machines. Many companies offer financial incentives such as gift cards to entice workers to participate in these programs. Many of the programs require employees to complete health risk assessments (HRAs), which are questionnaires that often ask individuals to disclose personal health information such as genetic risk for disease.

What is a wellness program? One would expect that the concept would be tightly defined in the rules. However, the Equal Employment Opportunity Commission (EEOC) rules provide that wellness programs must be ''reasonably designed,'' defined as having a ''chance'' at promoting health. Remarkably, no actual wellness services are required. This seems to mean that an employer can ''design a program'', perhaps blocking all of the nearby parking spaces, or putting only health drinks in the soda machine, and as long as they share the results of any examinations, they have fulfilled the letter of the law. There is also no requirement that the employer destroy any information once the employee discontinues participation in a program or leaves the employer.

The health benefits of providing employee wellness programs are seemingly intuitive. However, evidence of their benefit is sparse and even when available it is not clear cut (Misra-Hebert *et al.*, 2016). There is a good deal of concern that wellness programs are ''data-mining'' operations to collect and compile health information from many sources, then sell it to data companies, marketers, and other ''business partners'' (www.shrm.org/hrdisciplines/technology/articles/pages/wellness-programs-raise-privacy-concerns-over-health-data.aspx). Consent to do this is not transparent and might be through the terms of use on a website used to answer a HRA—perhaps the only way to avoid the wellness penalty.

The Genetic Information Nondiscrimination Act (GINA) and the Americans with Disabilities Act were instrumental in protecting individuals from inquiries into their genetic predisposition for diseases and/or existing disabilities. Both acts, however, provide exceptions in the law with regard to voluntary medical examinations as part of an employee health program. It appears that ''voluntary'' no longer means voluntary.

In May 2016, the EEOC issued a final rule that amends GINA regulations as they relate to employer incentives for participation in employer-sponsored wellness programs. The rule redefines ''voluntary'' participation in these wellness programs, allowing employers to penalize employees and their families up to 30% of both the employee and the employer portions of the lowest cost major medical self-only plan if they refuse to answer questions relating to their health status. Taken for both the employee and their spouse, this is potentially a 60% penalty! According to the Kaiser Family Foundation/Heath Research & Education Trust 2015 Survey of Employer Health Benefits, annual premiums for employer-sponsored family health coverage was $17,545, an increase of 4% from the previous year, with workers paying on average $4955 of the cost of their coverage. This cost could even be greater for older workers. Given the rising costs of health insurance each year, it is easy to see how these penalties could be catastrophic to many families. Taking this into consideration, a ''voluntary'' program may seem ''mandatory.''

In addition to the threat of financial penalties due to noncompliance, the new regulations severely undermine protections against discrimination and participant privacy, which is a drastic weakening of the protections afforded by GINA. If employees wish to have affordable healthcare and avoid lofty penalties, they could be forced to give up private medical and genetic information to employer-sponsored wellness

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programs. GINA strictly mandates protections for family medical history, which includes information about an individual's genetic testing as well as information regarding manifestation of a disease or disorder in the individual's family members. The new GINA regulations, however, require workers and their spouses to disclose personal health information, which also constitutes genetic information on their children, which is currently expressly prohibited by GINA.

Furthermore, although participants may consent to providing their employer with genetic information to participate in workplace wellness programs, they may not necessarily agree with the ''sale'' of this information to other companies. Although the new GINA regulations prohibit programs from requiring employees to agree to the ''sale'' of their health information to participate, as already described, clever wording in their terms of use allows them to create a loophole in which employers are permitted to ''share'' the information with business partners.

These new regulations undermine important protections against discrimination and compromises participant privacy. This could ultimately dissuade individuals from participating in research programs like the Precision Medicine Initiative, as any information discovered through this important research effort could then be obtained by their employers. The Precision Medicine Initiative, and other large-scale studies, requires large cohorts of participants to develop personalized therapies to prevent and treat disease, but this initiative cannot be realized if participants are not assured of the confidentiality of their participation. It is also not clear how information from wearables will be treated.

Reference

Misra-Hebert AD, Hu B, Taksler G, *et al.* (2016) Financial incentives and diabetes disease control in employees: a retrospective cohort analysis. J Gen Intern Med [Epub ahead of print]. www.ncbi.nlm.nih.gov/pubmed/27067350

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