

Genetic Testing and the Workplace

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AN EXCERPT FROM comments submitted to the equal employment opportunity commission (EEOC) docket. The EEOC invited comments in January 2016 on a proposed rule to amend regulations implementing Title II of the Genetic Information Nondiscrimination Act (GINA, RIN 3046-AB02) as they relate to employer wellness programs. Genetic Alliance and more than 600 organizations and individuals opposed the GINA notice of proposed rule making (GINA NPRM).

Three key provisions in the NPRM weaken GINA protections:

1. The NPRM redefines “voluntary” wellness program to mean “mandatory” for most people—under current regulations, employers (covered entities) are prohibited from requesting individuals to take a genetic test or disclose genetic information. One of the exceptions is if such requests are made through a voluntary workplace wellness program. By making requests through these programs, the covered entity neither requires the individual to provide genetic information nor penalizes those who choose not to provide it. The GINA NPRM proposes to redefine the definition of “voluntary” in a way that would permit employers to severely penalize families unless they provide access to their personal health information. The GINA NPRM attempts to counteract the problem it creates by retaining select protections for genetic information (notice rules, consent requirements, and prohibition on conditioning inducements on the disclosure of genetic information) and by adding a new requirement (which prohibits conditioning participation on agreement to the sale of one’s genetic information or on the waiver of privacy protections for genetic information). However, these protections will be rendered ineffective by two other concerning changes proposed in the GINA NPRM:
2. The NPRM adopts a standard for “reasonably designed” wellness program that is meaningless—the GINA NPRM adopts the definition of a “reasonably designed” workplace wellness program that was originally proposed in the Bush Administration¹ and subsequently embraced by the Obama Administration² in regulations implementing the Affordable Care Act

(ACA) workplace wellness standards. This standard is intentionally vague and flexible and requires no scientific evidence of efficacy, only the sponsor’s claim that it has a reasonable chance of promoting health. The ACA rule notes that the reasonably designed standard is intended to be easy to satisfy and to allow experimentation by employers.³ Under this definition, for example, a workplace wellness program could claim to be reasonably designed if it gathers up all available personal health information on participants—not only through health risk assessments and biometric screening but also from participants’ medical records, health insurance claims data, and other sources—and then uses and shares information with other commercial partners who also want access to the information for marketing and other purposes.⁴

3. The NPRM weakens protections for the form of genetic information called family medical history—the third fundamental weakening of GINA protections is accomplished by the NPRM effectively changing the definition of genetic information under federal law. GINA defines genetic information to include information about an individual’s genetic tests and the genetic tests of an individual’s family members, as

³Seventy-eight *Federal Register* at 33162.

⁴So-called reasonably designed workplace wellness programs already are using genetic testing. For example, one wellness vendor offers a program that encourages individuals to undergo genetic testing for metabolic syndrome risk, even though medical experts question the validity of this test (see: www.dallasnews.com/business/health-care/20150428-genetic-testing-moves-into-world-of-employee-health.ece). Under this program, participants complete a health risk assessment and biometric screening (which they would be financially compelled to do under the NPRM) and are offered a genetic test to assess their risk of developing metabolic syndrome. The wellness vendor also markets its products—so called genetically engineered vitamins and nutritional supplements—to individuals it determines to be at risk for metabolic syndrome. Terms of use and privacy links on the vendor’s website note that this is a Canadian corporation, not subject to the laws of the United States, although it also describes Health Insurance Portability and Accountability Act (HIPAA) protections in detail. These documents also state that personal information collected through the wellness program can be used and disclosed to market the vendor’s own products and services to participants, and to send participants offers that promote the products of other businesses. Participants agree to all of these terms by simply using the wellness program website. For examples, please see Attachment B from the comments as originally submitted, available at <http://geneticalliance.org/advocacy/policyissues/wellness/gina/>.

¹www.gpo.gov/fdsys/pkg/FR-2006-12-13/pdf/06-9557.pdf

²www.gpo.gov/fdsys/pkg/FR-2013-06-03/pdf/2013-12916.pdf

well as information about the manifestation of a disease or disorder in an individual's family members (i.e., family medical history). However, the NPRM would permit workplace wellness programs to compel both workers and their spouses to disclose their own personal health information, even though the spouse's health information constitutes genetic information of the worker and vice versa, and information on both parents constitutes genetic information of their children, which the NPRM insists should not be collected under any circumstances.

We recommended these changes to the NPRM:

1. Define "voluntary" to mean voluntary.
2. Adopt stronger standards for "reasonably designed" wellness programs that request genetic information and other personal health information.
3. GINA protections must apply to all genetic information, including family medical history.
4. Notice requirements must be strengthened and authorization should never be passively obtained.
5. Revise GINA and ADA NPRM to ensure that covered entities are the same.
6. Prohibit collection of genetic information about children of all ages.
7. Prohibit conditioning participation in wellness program on agreement permitting the sale of genetic information, or otherwise waiving confidentiality protections.
8. Prohibit conditioning inducements on agreement to provide genetic information.
9. Privacy protections for genetic information and other health information obtained by wellness programs must be strengthened.

In conclusion, we strongly reiterate that any employer request for genetic information or other personal health information should be subject to the strongest possible standards. Such requests should only be permitted through wellness plans that are truly voluntary and truly reasonably designed, and even then, strong notice, authorization, and privacy requirements should apply, as should reporting requirements on employers to promote accountability and enforcement.

To read the complete response to the NPRM, please visit: <http://geneticalliance.org/advocacy/policyissues/wellness/gina>

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