Employer Wellness Programs and Genetic Information: Frequently Asked Questions

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Since the passage of the Patient Protection and Affordable Care Act of 2010 (ACA, P.L. 111-148, as amended), which encouraged the use of wellness programs, employers have increasingly established employer wellness programs in an effort to support better health among their employees and reduce their own health care costs.[1] Employer wellness programs often focus on improving wellness overall, but they may target a specific disease (e.g., diabetes) or behavior (e.g., smoking), and they may include the provision of health or other services. These programs often include incentives for participation, ranging from additional paid time off to reduced insurance premium contributions.[2]

Participation in a wellness program almost always involves the provision of medical information—which may include genetic information—by the participant (e.g., the employee, the employee's spouse) to the employer. The Equal Employment Opportunity Commission (EEOC) permits employers to request genetic information as part of a wellness program but prohibits the offering of inducements to secure such information. In other words, the EEOC requires that the provision of genetic information as part of a wellness program be voluntary, and considers the offering of any incentive at all for the provision of genetic information to nullify this voluntariness.[3]

In certain cases, an employee's family members—for example, a spouse—may be given the option of participating in a wellness program offered by their family member's employer. The EEOC recently released a notice of proposed rulemaking to address the issue of when an employer may lawfully provide incentives to an employee's spouse for the provision of certain of his or her own medical information as a participant in an employer wellness program.[4]

This report explains when an employer may request genetic information from an employee as part of a wellness program with an inducement attached to participation and the requirements the employer must follow when doing so. It also discusses the EEOC's proposed rule whereby a spouse may be incentivized to provide his or her own medical information, which is also the employee's genetic information, as part of a wellness program.

What is genetic information?

Genetic information of an individual is defined in statute as information about (1) an individual's genetic tests, (2) the genetic tests of family members of such individual, and (3) the manifestation of a disease or disorder in family members of such individual.[5] The statute defines "family member" to include relatives out to the fourth degree (e.g., great-grandparent), as well as dependents of the individual.[6] Dependents are persons who are or who become related to an individual through marriage, birth, adoption, or placement for adoption, and includes spouses.[7]

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[1] See http://www.cdc.gov/workplacehealthpromotion/index.html.

[2] For more information on employer wellness programs in the context of the ACA, see pp. 41-43, CRS Report R41278, *Public Health, Workforce, Quality, and Related Provisions in ACA: Summary and Timeline*, coordinated by (name redac ted) and (name redacted) .

[3] 75 FR 68935, November 9, 2010.

[4] 80 FR 66853, October 30, 2015.

[5] 42 U.S.C. 2000ff.

[6] 42 U.S.C. 2000ff.

[7] 75 FR 68914, November 9, 2010. The definition for "dependent" includes relatives that are not blood-related (e.g., spouse, adopted child). This is due to the fact that the definition is partially determined by reference to the use of the term under Section 701(f)(2) of the Employee Retirement Income Security Act of 1974 (ERISA), a statute concerned primarily with employee benefits, including retirement and health benefits. Despite the fact that individuals who are not (continued...)

Can an employer request genetic information from an employee as part of a wellness program?

Yes, an employer may request—but not require—an employee to provide his or her own genetic information as part of a wellness program. Most if not all employer wellness programs collect medical information from participants, and employers may ask participating employees to answer questions about their own health and family medical history. Some of this information—for example, family medical history—falls under the definition of genetic information in Title II of the Genetic Information Nondiscrimination Act of 2008 (P.L. 110-233, GINA), and therefore its acquisition by employers is protected and is protected differently than is employer acquisition of other medical information.[8]

Must the provision of genetic information by an employee to an employer as part of a wellness program be voluntary?

Yes, the provision of genetic information by an employee (or any individual) to an employer as part of a wellness program must be voluntary, an issue that arises especially where participation in wellness programs is incentivized and the provision of medical information is often a requirement of participation. On November 9, 2010, the EEOC issued final regulations for Title II of GINA that clarify that an employee's provision of his or her own genetic information as part of a wellness program must be voluntary, and explains what that means.[9] Specifically, the final rule requires that "the provision of genetic information by the individual is voluntary, meaning the covered entity neither requires the individual to provide genetic information nor penalizes those who choose not to provide it."[10]

How must an employer request genetic information as part of a wellness program?

Although GINA does allow for the voluntary collection of genetic information as part of an employer wellness program, this exception is subject to certain statutory and regulatory requirements.[11] Employers may collect genetic information as part of a wellness program, pursuant to this exception, only if they meet three requirements, as specified by GINA:

1. the employee must provide prior, knowing, voluntary, and written authorization;

(...continued)

blood-related do not share any genetic material, the EEOC determined that for purposes of Title II of GINA, dependents include "persons who are or become related to an individual through marriage, birth, adoption, or placement for adoption." The EEOC goes on to say that this decision was made because 1) the reference to ERISA made clear Congress' intent to include dependents by adoption or marriage in the definition; and 2) information about the health of these dependents could be used by an employer to discriminate in health insurance based on higher health costs of the dependent, something that GINA was intended to prohibit.

[8] For more information, see CRS Report RL34584, *The Genetic Information Nondiscrimination Act of 2008 (GINA)*, by (name redacted) and (name redacted)

[9] 29 CFR Part 1365, "Regulations Under the Genetic Information Nondiscrimination Act of 2008; Final Rule."

[10] 75 FR 68935, November 9, 2010.

[11] 42 U.S.C. 2000ff-1(b)(2).

2. only the employee and the licensed health care professional or board-certified genetic counselor involved in providing such services receive individually identifiable information concerning the results of such services; and
3. any individually identifiable genetic information provided in connection with the health or genetic services provided under this exception is only available for the purposes of such services and shall not be disclosed to the employer except in aggregate terms that do not disclose the identity of specific employees.

The regulations implementing GINA require that a health risk assessment (HRA)—the survey often given to participants in wellness programs to collect their health information—must clearly and understandably indicate that the provision of any genetic information asked for on the HRA is not linked to any incentive. Specifically, the final rule explains that an employer "may not offer a financial inducement for individuals to provide genetic information, but may offer financial inducements for completion of health risk assessments that include questions about family medical history or other genetic information, provided the covered entity makes clear ... that the inducement will be made available whether or not the participant answers questions regarding genetic information."[12]

Does the prohibition on the use of genetic information to discriminate in employment decisions still stand, regardless of how an employer were to acquire such information?

Yes, importantly, regardless of how an employer may acquire genetic information (through this exception or any other lawful exception), the employer—including employers, unions, employment agencies, and labor management training programs—is still absolutely prohibited from using the information to discriminate in employment decisions, such as hiring, firing, and promotion.

What issues arise with respect to the collection of an employee's family member's medical information as a part of a wellness program?

Often, an employee's family members—for example, a spouse—may be given the option of participating in an employer wellness program. This raises issues with respect to the prohibition on offering an inducement in exchange for the provision of genetic information. Specifically, the statutory definition of genetic information is such that if a spouse or child provides *his or her own* current or past health status, that information is not the spouse or child's genetic information under GINA's definition. However, it is still the genetic information of the *employee*.

For example, if a spouse provides information about his or her current or past health status (e.g., high cholesterol), that is not genetic information about the spouse, but it would be considered genetic information about the employee, because it is the employee's family history (i.e., family history of high cholesterol), and this information is genetic information under GINA. Therefore, if an employee's spouse provides current health information as part of an employer wellness program, and receives an incentive for doing so, the employee's spouse has received an incentive for providing certain genetic information about his family member (who is also an employee).

[12] 75 FR 68935, November 9, 2010.

The end result is that the employer has genetic information about an employee, and the employer provided an incentive (to the spouse) to provide that genetic information. Although this information is legally defined as genetic information, it is not biologically genetic information; that is, nothing about the spouse's current or past health status has any bearing on the genetic makeup—and therefore likelihood of manifesting a disease or condition—of the employee. However, the health status of an employee's spouse could potentially be used by an employer to discriminate against the employee out of concern about higher overall health care costs.[13]

What does the EEOC's proposed rule say about a spouse providing his or her own current or past health status as part of an employer wellness program with an incentive?

Recently, the EEOC released a notice of proposed rulemaking (NPRM) addressing the issue of providing incentives for the collection of a spouse's current and past health status as part of a wellness program.[14] The EEOC's rule proposes to allow the employer to incentivize the spouse—but not the employee—to provide information about his or her own current or past health status (e.g., blood pressure, diabetes). It does not allow for the employer to incentivize the spouse to provide his or her own genetic information, however (e.g., results of a genetic test, family history).

Would the EEOC's proposed rule allow an incentive for the collection of an employee's child's current or past health status as part of an employer wellness program?

No, the EEOC's rule would prohibit the practice of providing an incentive in exchange for an employee's children's current or past health status. The EEOC explains in the NPRM that it proposes to draw the exception (above, for incentives in exchange for the spouse's current or past health status) as narrowly as possible, and therefore does not include an employee's children's information within the exception.[15] In addition, in terms of the nature of genetic information, the employee actually shares genetic material with his biological children, and so a child's health status information would be more informative with respect to an employee than would an employee's spouse's health status information.

Would the incentive for a spouse to provide his or her own current and past health status as part of a wellness program be capped?

Yes, the incentive to both the spouse and the employee would be capped at 30% of the total annual cost of family health insurance coverage. EEOC points out that this limit is consistent with limits for inducements established by the ACA.[16]

[13] 75 FR 68915, November 9, 2010.

[14] 80 FR 66853, October 30, 2015.

[15] 80 FR 66856, October 30, 2015.

[16] 80 FR 66857, October 30, 2015.

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