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EEOC Issues Long-Awaited Final Regulations on the Genetic Information Nondiscrimination Act

By Ilyse Schuman

Nearly a year after the employment provisions of the Genetic Information Nondiscrimination Act (GINA) took effect, the Equal Employment Opportunity Commission (EEOC) has issued a final rule (pdf) implementing these sections. Title II of GINA – which took effect on November 21, 2009 and applies to the same covered entities as Title VII of the Civil Rights Act of 1964 – prohibits the use of genetic information in making employment decisions, restricts acquisition of genetic information by employers and other entities covered by Title II, and strictly limits the disclosure of genetic information. Title II also prohibits retaliation against employees who complain about genetic discrimination. According to the EEOC, the final rule implements the various provisions of Title II consistent with Congress's intent, provides some additional clarification of those provisions, and explains in greater detail those sections where Congress incorporated by reference provisions from other statutes.

Definitions

The final rule retains the language from the proposed regulations that includes applicants and former employees in the definition of *employee*. Therefore, GINA's protections extend not only to current employees, but to applicants and former employees as well.

The final rule also provides some additional guidance on terms that are unique to GINA. For the definition of *family member*, the rule stipulates that dependents covered by Title II are limited to persons who are or become related to an individual through marriage, birth, adoption, or placement for adoption. The EEOC explains that even though adoptees might not be genetically related to the covered employee, "the acquisition of information about the occurrence of a disease or disorder in an applicant's or employee's adopted child could certainly result in the type of discrimination GINA was intended to prohibit," and therefore is included in the definition.

The term *genetic information* is defined as information about: (1) an individual's genetic tests; (2) the genetic test of that individual's family members; (3) family medical history; (4) an individual's request for, or receipt of, genetic services, or the participation in clinical research that includes genetic services by the individual or family member of the

individual; or (5) genetic information of a fetus carried by an individual or by a pregnant woman who is a family member of the individual and the genetic information of any embryo legally held by the individual using an assisted reproductive technology.

With respect to the definition of *family medical history*, the EEOC declined to limit such information to “inheritable” diseases or disorders. In addition, the EEOC had invited comments on the scope of the term “genetic test.” In response, the final rule includes examples of the kinds of tests that are considered *genetic tests*. The final rule also includes examples of tests that are not considered genetic tests, such as complete blood counts, cholesterol tests, and liver-function tests. In addition, a test for the presence of alcohol or illegal drugs is not considered a genetic test.

Prohibited Acts

Under GINA, employers are prohibited from discriminating against employees on the basis of genetic information in regard to hiring, discharge, compensation, terms, conditions, or privileges of employment. In the preamble to the final rule, the EEOC notes that claims of harassment on the basis of genetic information are cognizable.

GINA prohibits employers from limiting, segregating, or classifying employees based on genetic conditions. The rule clarifies, however, that an employer may limit or restrict an employee’s job duties based on genetic information if it is required to do so by a law or regulation that mandates genetic monitoring, such as regulations administered by the Occupational Safety and Health Administration (OSHA). The rule also confirms that neither the statute nor the final regulation creates a cause of action for disparate impact.

GINA prohibits employment agencies, labor organizations, and apprenticeship or other training programs from causing an employer to discriminate on the basis of genetic information. The rule notes that because GINA incorporates Title VII’s definition of employer, including the application of common law agency principles, the law prohibits an employer from engaging in actions that would cause another entity acting as its agent to discriminate. For instance, an employer cannot ask an employment agency to screen its candidates in a manner that would violate GINA.

The final rule reiterates the statutory prohibition against retaliation because an individual opposes any act made unlawful by GINA, files a charge of discrimination or assists another in doing so, or gives testimony in connection with a charge. The EEOC’s interpretation is that Congress intended that the standard for determining retaliation claims under GINA be the same standard as under Title VII claims as set forth in *Burlington Northern & Santa Fe Ry. v. White*.¹

Acquisition of Genetic Information

GINA prohibits employers from requesting, requiring, or purchasing genetic information about an employee or family member except in limited circumstances. The EEOC removed reference to the “*deliberate* acquisition” of genetic information, which had been included in the proposed regulations, in response to comments that the use of the term “*deliberate* acquisition” of genetic information suggested that an employer must have a specific intent to acquire genetic information to violate the law. The EEOC agreed that employers can violate GINA without a specific intent to violate the law by engaging in activity that presents a “heightened risk” of acquiring genetic information, such as when employers fail to inform an individual from whom they have requested documentation about a manifested disease or disorder not to provide genetic information.

The final rule provides that a *request* for genetic information:

includes conducting an Internet search on an individual in a way that is likely to result in a covered entity obtaining genetic information; actively listening to third-party conversations or searching an individual’s personal effects for the purpose of obtaining genetic information; and making requests for information about an individual’s current health status in a way that is likely to result in a covered entity obtaining genetic information.

The new rule clarifies, however, that “a request for information about whether an individual has a manifested disease, disorder, or pathological condition does not violate GINA simply because a family member of the individual to whom the request was made works for the same employer, is a member of the same labor organization or is participating in the same apprenticeship program as the person from whom the information was requested.”

The final rule attempts to provide greater clarity on the following situations in which the prohibition against acquiring genetic information does not apply.

Inadvertent Receipt of Genetic Information

An employer that inadvertently requests or requires genetic information of an individual or family member does not violate GINA. As the EEOC notes, Congress intended this exception to address the so-called “water cooler problem,” in which employers unwittingly receive genetic information through casual conversation with an employee or overhearing conversations among co-workers. Although the language of this exception in the statute refers only to family medical history, the EEOC applies the exception to any genetic information that the employer inadvertently acquires. The EEOC provides examples intended to clarify the exception for inadvertent acquisition of genetic information. For example, an employer would not violate GINA if a casual conversation or a general question, such as “how are you?” or “how is your son feeling today,” inadvertently elicits genetic information. An employer, however, could not ask follow-up questions such as whether other family members also have the condition or whether the individual has been tested.

The final rule also includes a “safe harbor” provision explaining that when an employer warns anyone from whom it requests health-related information not to provide genetic information, it is not liable under GINA if the individual provides genetic information to the employer. If the employer acquires genetic information in response to a lawful request for medical information, the acquisition of genetic information will not generally be considered “inadvertent” unless the employer directs the individual and/or health care provider not to provide genetic information. The final rule includes a model notice that the employer can use for satisfying the “safe harbor” warning.

The EEOC also notes that a warning is mandatory when an employer requests a health care professional to conduct an employment-related medical examination on the employer’s behalf. Although employers may conduct post-offer, pre-employment medical examinations or fitness-for-duty examinations consistent with the ADA, employers may not request or require an individual to provide genetic information during the examination. Moreover, an employer must affirmatively tell health care providers not to collect genetic information as part of a medical examination intended to determine the ability to perform a job. Employers must also take additional reasonable measures within their control if they learn the genetic information is being requested or required. The EEOC, however, clarifies that Title II of GINA does not apply to medical examinations conducted for the purpose of diagnosis and treatment that are unrelated to employment. For instance, a hospital conducting a medical examination of an individual who happens to work there would not be subject to Title II restrictions, so long as the examination is unrelated to the individual’s employment.

An example of the inadvertent acquisition of genetic information is when an employer requests medical documentation in response to an employee’s request for a reasonable accommodation under the Americans with Disabilities Act (ADA). The final rule cautions, however, that “in order to be considered a lawful request for documentation made in response to an individual seeking a reasonable accommodation under the ADA or state or local law, the request for medical documentation can be made only when the disability and/or the need for accommodation is not obvious.” The EEOC adds that, like any request for medical documentation, the request for documentation as part of the reasonable accommodation process should include the warning and notice language noted above.

An employer that inadvertently receives genetic information in response to a lawful request for medical information as part of an employee’s request for leave under the Family and Medical Leave Act (FMLA) or state or local leave law for his own serious health condition would not violate GINA. According to the EEOC, acquisition of genetic information in such a situation is considered inadvertent “if the covered entity affirmatively warns individuals and health care providers from whom they are seeking medical documentation not to provide genetic information, or, in the absence of such a warning, where the request for medical information was not likely to result in the acquisition of genetic information.” The EEOC also extends the exception for the inadvertent acquisition of genetic information requests to leave under an employer’s leave policy independent of federal, state, or local leave or disability law.

Wellness and Disease Management Programs

GINA also allows employers and other covered entities to obtain genetic information in connection with employer-provided health or

genetic services, including wellness programs, as long as any individually identifiable genetic information that discloses the identity of the employee is accessible only to the employee and the health care provider involved in providing such services. Additionally, the individual participating in the program must provide prior knowing, voluntary, and written authorization. This means that the employer must use an authorization form that is written in language that is “reasonably likely to be understood by the individual from whom the information is sought; describes the information being requested; and describes the safeguards in place to protect against unlawful disclosure.” The employer may not receive individually identifiable genetic information.

The proposed rule did not define the term “voluntary” for purposes of this exception. Many commenters sought clarification regarding the permissible level of inducement to participate in a wellness program an employer could provide without running afoul of GINA. Interim Final Regulations implementing Title I of GINA, which applies to group health plans sponsored by private employers, unions, and state and local government employers, issuers in the group and individual health insurance markets, and issuers of Medicare supplemental (Medigap) insurance, prohibit a group health plan from offering a financial incentive for completion of a health risk assessment that seeks genetic information, including family medical history. Concerns have been raised that this interpretation would chill the use and effectiveness of wellness programs. Such a restriction appears contrary to provisions of the Patient Protection and Affordable Care Act designed to encourage the use of wellness programs.

In the final GINA Title II regulations, the EEOC takes a position similar to the Title I regulations, concluding that “covered entities may offer certain kinds of financial inducements to encourage participation in health or genetic services under certain circumstances, but they may not offer an inducement for individuals to provide genetic information.” For example, an employer could offer incentives to employees that complete a health risk assessment that includes questions about family medical history or other genetic information so long as the employer specifically identifies those questions and makes clear that the participant need not respond to those questions that request genetic information to receive the incentive. Such a “bifurcated” health risk assessment would not violate Title II of GINA.

The final rule also allows employers to offer financial inducements for participation in disease management programs based on voluntarily provided genetic information as long as the employer offers the program and inducements to individuals with current health conditions and/or individuals whose lifestyle choices put them at increased risk of developing a condition.

Compliance with FMLA Certification Requirements

GINA allows employers to request family medical history to comply with the certification requirements of the FMLA or state or local family and medical leave laws. Employers may also request family medical history pursuant to a policy, even in the absence of a leave law, that permits the use of leave to care for a sick family member and that requires all employees to substantiate the need for leave with information about the health conditions of family members.

Publicly Available Information

GINA makes an exception for genetic information obtained from publicly available sources. Many commenters requested further explanation of what constitutes a “publicly available” source. In response, the EEOC notes that if a media source, such as a database or website, requires permission for access from a specific individual, as opposed to a media source that similarly requires users to obtain a username and/or password, or if access is conditioned on membership in a particular group, such as a professional organization, then the acquisition of genetic information through these channels does not fall under the “publicly available” exception. Thus, the determining factor is “whether access requires permission of an individual or is limited to individuals in a particular group, not whether the source is categorized as a social networking site, personal website, or blog.”

The rule explains that intent can be a factor in determining whether an entity violates Title II. For example, if an employer intentionally performs an internet search to see if an employee or applicant has a genetic condition, he or she violates GINA even if the information is discovered on a publicly available site.

Similarly, the exception will not apply if an employer obtains information from a media source, whether or not it is commercially and publicly available, if the employer is likely to obtain genetic information from that source, such as a website or database that focuses on genetic testing and/or contains individually identifiable health information.

Genetic Monitoring

GINA permits employers to engage in genetic monitoring of the biological effects of toxic substances in the workplace, provided they notify employees that they will do so, and where not required by law to conduct such monitoring, obtain the individual's consent. The final rule also includes a provision stating that an employee who refuses to participate in a voluntary genetic monitoring program cannot be discriminated against on that basis.

DNA Analysis

GINA also permits employers that engage in DNA testing for law enforcement or human remains identification purposes to request or require genetic information of its employees.

Disclosure of Genetic Information

Employers that possess written genetic information are required to store such information in a separate confidential medical file, as required under the ADA. However, genetic information placed in personnel files before November 21, 2009, need not be removed.

Ordinarily, the disclosure of genetic information is prohibited under GINA. The Act, however, lays out a number of exceptions to this rule. For example, GINA permits an employer to disclose genetic information to the employee or family member to whom the information relates upon written request. Employers may also disclose genetic information to an occupational or other health researcher if the research is conducted according to applicable federal regulations. Employers may also disclose genetic information if compelled by court order. The rule explains that this exception does not allow disclosures in other circumstances during litigation, such as in response to discovery requests or subpoenas that are not governed by an order specifying that genetic information must be disclosed. Therefore, an employer's refusal to provide genetic information in response to a discovery order, subpoena, or court order that does not specify that genetic information must be disclosed is consistent with the requirements of GINA.

Yet another exception allows an employer to disclose relevant genetic information consistent with the requirements of the FMLA or similar state or local law. As an example, the rule explains that an employee's supervisor who receives a request for FMLA leave from an employee who wants to care for a child with a serious health condition may forward this request to those who need to know the information because of responsibilities relating to the handling of FMLA requests. Employers may also disclose genetic information to government officials investigating compliance with GINA and to public health officials in connection with a contagious disease that presents an imminent hazard of death or life-threatening illness.

Liability Under Title I and Title II of GINA

Title I of GINA, which applies generally to group health plans, prohibits discrimination in group premiums based on genetic information and the use of genetic information as a basis for determining eligibility or setting premiums, among other things. The Title II rule includes a section creating a "firewall" between GINA Titles I and II so that violations of Title I are addressed and remedied under the regulations applicable to Title I and not through Title II and other employment discrimination procedures. The new rule explains, however, that employers could still face liability under Title II even if their actions involve access to health benefits, "because such benefits are within the definition of compensation, terms, conditions, or privileges of employment." Examples of such liability include the following situations:

- If an employer contracts with a health insurance issuer to request genetic information, the employer has committed a Title II violation. In addition, the plan and issuer may have violated Title I of GINA.
- If an employer directs its employees to undergo mandatory genetic testing in order to be eligible for health benefits, the employer has committed a Title II violation.
- If an employer or union amends a health plan to require an individual to undergo a genetic test, then the employer or union is liable for a violation of Title II. In addition, the health plan's implementation of the requirement may violate Title I.

The rule emphasizes that the anti-discrimination provisions in GINA do not require employers to provide employees with any specific benefits or specialized health coverage, or offer health benefits that relate to any specific genetic disease or disorder.

Practical Steps for Employers

Although the final rule does provide additional clarity on key provisions of GINA, some uncertainty remains. The application of the “water cooler” exception to the prohibition on the acquisition of genetic information is likely to generate questions and claims despite the additional direction from the EEOC. What is clear is that employers must revisit their policies and practices to ensure compliance with GINA. Employers should take the following steps:

- Train human resources personnel, managers, recruiters about compliance with GINA.
- Revise EEO policies to include prohibitions against discrimination based on genetic information and associated retaliation.
- Discontinue any request or requirement to provide family medical history or other genetic information in connection with an employee’s request for a reasonable accommodation under the ADA, for FMLA leave for the employee’s own serious health condition, or pursuant to a leave or disability policy; add the “safe harbor” warning that the employee and/or health care provider must not provide genetic information.
- Discontinue any request or requirement to provide genetic information during an employment-related medical examination such as in connection with a post-offer, pre-employment medical examination, or a fitness-for-duty exam. Employers must instruct health care providers not to collect genetic information as part of the employment-related medical examination.
- If the employer offers a financial inducement for completing a health risk assessment that includes questions about family medical history or other genetic information, the employer must specifically identify such questions and clearly state that the inducement will be provided whether or not the participant answers the questions concerning family medical history or other genetic information.
- Inventory personnel records – such as FMLA certifications seeking leave for the serious illness of a family member – that contain genetic information about an employee, store those records in a confidential medical file, and strictly limit access to those with a need to know.
- Implement procedures to prevent the disclosure of genetic information in response to a subpoena or civil discovery and to permit disclosure only when specifically required to comply with a court order.

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¹ 548 U.S. 53 (2006).