

Background Information for EEOC Notice of Proposed Rulemaking on Title II of the Genetic Information Nondiscrimination Act of 2008

On May 21, 2008, the President signed the [Genetic Information Nondiscrimination Act of 2008](#) (GINA). GINA includes two titles. Title I, which amends portions of the Employee Retirement Income Security Act (ERISA), the Public Health Service Act, and the Internal Revenue Code, addresses the use of genetic information in health insurance. Title II prohibits the use of genetic information in employment, prohibits the intentional acquisition of genetic information about applicants and employees, and imposes strict confidentiality requirements.

GINA requires the Equal Employment Opportunity Commission (EEOC) to issue regulations implementing Title II of the Act. EEOC published a [Notice of Proposed Rulemaking](#) (NPRM) on March 2, 2009, under that authority. The public comment period on the NPRM ended on May 1, 2009.

Who must comply with Title II of GINA?

Title II applies to private and state and local government employers with 15 or more employees, employment agencies, labor unions, and joint labor-management training programs. It also covers Congress and federal executive branch agencies. The NPRM and this document use the term “covered entity” to refer collectively to all entities subject to Title II of GINA.

Are entities subject to Title II of GINA required to comply with the law now?

No. There will be some time between issuance of final regulations and the date on which the law becomes effective and entities need to begin complying with it. Title II of GINA is effective on **November 21, 2009**.

Why is GINA needed?

GINA was enacted, in large part, in recognition of developments in the field of genetics, the decoding of the human genome, and advances in the field of genomic medicine. Genetic tests now exist that can inform individuals whether they may be at risk for developing a specific disease or disorder. But just as the number of genetic tests increase, so do the concerns of the general public about whether they may be at risk of losing access to health coverage or employment if insurers or employers have their genetic information.

Congress enacted GINA to address these concerns, by prohibiting discrimination based on genetic information and restricting acquisition and disclosure of such information, so that the general public would not fear adverse employment- or health coverage-related

consequences for having a genetic test or participating in research studies that examine genetic information.

What is “genetic information?”

The statute and the NPRM include a detailed description of what constitutes “genetic information.” Genetic information includes, for example, information about an individual’s genetic tests, genetic tests of a family member, and family medical history. Genetic information does not include information about the sex or age of an individual or the individual’s family members, or information that an individual *currently has* a disease or disorder. Genetic information also does not include tests for alcohol or drug use. The Commission specifically invites public comment on other kinds of tests that covered entities may conduct and whether they should be considered genetic tests.

What practices are prohibited by GINA Title II?

Title II of GINA prohibits use of genetic information in making decisions related to any terms, conditions, or privileges of employment, prohibits covered entities from intentionally acquiring genetic information, requires confidentiality with respect to genetic information (with limited exceptions), and prohibits retaliation.

Are there any exceptions to the prohibition on use of genetic information?

No. **This prohibition is absolute.** Covered entities may not use genetic information in making employment decisions under any circumstances.

Are there any exceptions to the general rule against acquisition of genetic information?

Yes. Although the general rule is that covered entities may not request, require, or purchase genetic information with respect to an employee/applicant or family member of an employee/applicant, there are exceptions.

One exception, sometimes referred to as the “water cooler” exception, applies to inadvertent acquisition of genetic information. This may occur, for example, where a supervisor overhears a conversation between co-workers in which genetic information is discussed or receives genetic information in response to a question about the general health of an employee or employee’s family member, or where an employer receives genetic information as part of documentation an employee submits in support of a request for reasonable accommodation under the Americans with Disabilities Act (ADA) or other similar law. Other exceptions are described in the statute and the NPRM.

What are GINA’s rules on confidentiality?

Covered entities in possession of genetic information about applicants or employees must treat it the same way they treat medical information generally. They must keep the

information confidential and, if the information is in writing, must keep it apart from other personnel information in separate medical files. A covered entity may keep genetic information in the same file as medical information subject to the ADA.

There are limited exceptions to GINA's prohibition on disclosure of genetic information, which are described in detail in the statute and NPRM.

Are disparate impact claims permitted under Title II of GINA?

No. However, the Act directs that a commission be formed six years after enactment to report on the possibility of allowing disparate impact claims.

Does Title II of GINA prohibit harassment?

Title II of GINA does not directly address the issue of harassment claims. However, in describing the prohibited practices under Title II, Congress adopted language similar to that used in Title VII of the Civil Rights Act of 1964 and other equal employment opportunity statutes, evincing its intent to prohibit discrimination with respect to a wide range of practices, including harassment.

Does Title II of GINA apply to employment decisions based on health benefits?

To some extent, yes. However, Title II of GINA includes a "firewall" provision intended to eliminate "double liability" by preventing claims under Title II from being asserted regarding matters subject to enforcement under Title I of GINA or the other genetics provisions for group coverage in ERISA, the Public Health Service Act, and the Internal Revenue Code. The firewall seeks to ensure that health plan or issuer requirements or prohibitions are addressed and remedied through ERISA, the Public Health Service Act, or the Internal Revenue Code and not through Title II and other employment discrimination procedures.

The firewall does not immunize covered entities from liability for decisions and actions taken that violate Title II, including employment decisions based on health benefits, because such benefits are within the definition of compensation, terms, conditions, or privileges of employment. For example, an employer that fires an employee because of anticipated high health claims based on genetic information remains subject to liability under Title II. On the other hand, acts or omissions relating to health plan eligibility, benefits, or premiums, or a health plan's request for or collection of genetic information remain subject to enforcement under Title I of GINA exclusively.

What effect does Title II of GINA have on other laws addressing genetic discrimination in employment?

Title II of GINA does not preempt any state or local law that provides equal or greater protections from employment discrimination on the basis of genetic information or improper access or disclosure of genetic information. Additionally, Title II of GINA does

not limit the rights or protections under Federal, state, local or Tribal laws that provide greater privacy protection to genetic information, and does not affect an individual's rights under the ADA, the Rehabilitation Act, or state or local laws that prohibit discrimination on the basis of disability.

However, Title II of GINA does limit an employer's ability to obtain genetic information after making a job offer. Although the ADA currently permits a covered entity to obtain family medical history or conduct genetic tests of job applicants once an offer of employment has been made, provided this is done for all entering employees in the same job category, such action will be prohibited upon the effective date of GINA.

What are the remedies for a violation of GINA Title II?

The same remedies available under Title VII are available under Title II of GINA. An aggrieved individual may seek reinstatement, hiring, promotion, back pay, injunctive relief, pecuniary and non-pecuniary damages (including compensatory and punitive damages) and attorneys' fees and costs. Title VII's cap on combined compensatory and punitive damages also applies to actions under Title II of GINA.¹ Punitive damages are not available against federal, state, or local government employers.

What happens now that the period for submitting comments on the NPRM has ended?

Following revision of the NPRM in light of public comments, the Commission will vote on a Final Rule. The Final Rule approved by the Commission will then be coordinated through the Office of Management and Budget with other Federal agencies before it is published in the Federal Register. EEOC anticipates that a Final Rule to implement Title II of GINA will be published well in advance of the law's effective date of November 21, 2009

To view public comments on the NPRM posted electronically, go to www.regulations.gov/fdmspublic/component/main?main=DocketDetail&d=EEOC-2009-0008. To view copies of the comments in EEOC's library, call (202) 663-4630 (voice) or (202) 663-4641 to schedule an appointment.

Footnotes

¹ The cap on combined compensatory and punitive damages (excluding past monetary losses) ranges from \$50,000 for employers with 15-100 employees to \$300,000 for employers with more than 500 employees.
