

Fact Sheet

The Genetic Information Nondiscrimination Act of 2008 (GINA)

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The Genetic Information Nondiscrimination Act of 2008 (GINA) prohibits discrimination in group health plan coverage based on genetic information. GINA is effective for plan years beginning after May 21, 2009 (January 1, 2010 for calendar year plans). Regulations implementing the provisions of GINA were made public on October 1, 2009.

Builds On HIPAA's Protections

GINA expands the genetic information protections included in the Health Insurance Portability and Accountability Act of 1996 (HIPAA). HIPAA prevents a plan or issuer from imposing a preexisting condition exclusion provision based solely on genetic information, and prohibits discrimination in individual eligibility, benefits, or premiums based on any health factor (including genetic information).

Additional Underwriting Protections

GINA provides that group health plans and health insurance issuers cannot base premiums for an employer or a group of similarly situated individuals on genetic information. (However, premiums may be increased for the group based upon the manifestation of a disease or disorder of an individual enrolled in the plan.)

Prohibits Requiring Genetic Testing

GINA also generally prohibits plans and issuers from requesting or requiring an individual to undergo a genetic test. However, a health care professional providing health care services to an individual is permitted to request a genetic test. Additionally, genetic testing information may be requested to determine payment of a claim for benefits, although the regulations make clear that the plan or issuer may request only the minimum amount of information necessary in order to determine payment. There is also a research exception that permits a plan or issuer to request (but not require) that a participant or beneficiary undergo a genetic test.

Restricts Collection Of Genetic Information

GINA also prohibits a plan from collecting genetic information (including family medical history) prior to or in connection with enrollment, or for underwriting purposes. Thus, under GINA, plans and issuers are generally prohibited from offering rewards in return for collection of genetic information, including family medical history information collected as part of a Health Risk Assessment (HRA). The regulations provide several examples illustrating GINA's application to HRAs.

An exception is included for incidental collection, provided the information is not used for underwriting. However, the regulations make clear that the incidental collection exception is not available if it is reasonable for the plan or issuer to anticipate that health information will be received in response to a collection, unless the collection explicitly states that genetic information should not be provided.

Other Protections

GINA also contains individual insurance market provisions, administered by the Department of Health and Human Services's Centers for Medicare & Medicaid Services, privacy and confidentiality provisions, administered by the Department of Health and Human Services's Office for Civil Rights, and employment-related provisions, administered by the Equal Employment Opportunity Commission (EEOC).

This fact sheet has been developed by the U.S. Department of Labor, Employee Benefits Security Administration, Washington, DC 20210. It will be made available in alternate formats upon request: Voice Telephone: 202.693.8664; Text Telephone: 202.501.3911. In addition, the information in this fact sheet constitutes a small entity compliance guide for purposes of the Small Business Regulatory Enforcement Fairness Act of 1996.