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Request for Information Regarding Sections 101 Through 104 of the Genetic Information Nondiscrimination Act of 2008

Comment On: IRS-2008-0103-0017
Interim Final Rules Prohibiting Discrimination Based on Genetic Information in Health Insurance Coverage and Group Health Plans

Document: IRS-2008-0103-0058
Comment on FR Doc # E9-22504

Submitter Information

Name: David Certner
Address:
P.O. Box 8017
Baltimore, MD, 21244-8010
Organization: AARP

General Comment

Comment Attach

Attachments

IRS-2008-0103-0058.1: Comment on FR Doc # E9-22504

January 5, 2009

Centers for Medicare and Medicaid Services
United States Department of Health and Human Services
Attention: CMS-4137-IFC
P.O. Box 8017, Baltimore, MD 21244-8010

RE: Interim Final Rules Prohibiting Discrimination Based on Genetic Information in Health Insurance Coverage and Group Health Plans; 74 Fed. Reg. 51663, October 7, 2009

AARP strongly supports the Interim Final Rule (IFR) prohibiting discrimination based on genetic information in health insurance and group health plans, published October 7, 2009 in the *Federal Register*. Implementation of the Genetic Information Nondiscrimination Act of 2008 (GINA) comes at an important time as Congress grapples with the larger questions of reforming our health system to make affordable coverage available to all Americans.

One important, widely-shared goal of the health reform effort is to end discrimination based on health-status, including genetic information. Use of genetic information as an underwriting tool is a serious concern, especially in workplace wellness programs that use health risk assessments (HRAs) to inquire about genetic-related family history and also increasingly determine employee cost sharing obligations. It is thus essential to ensure that effective safeguards are in place to prevent these programs from becoming a backdoor to discrimination based on genetic information or any other health factor. The IFR maintains GINA's integrity by establishing requirements consistent with the letter and intent of the law. We support the December 7th effective date for these regulations, and we strongly oppose any delay in enforcing these critical safeguards against use of genetic information as a tool for underwriting.

Definitions

Family Member: The IFR includes detailed definitions of first-, second-, third- and fourth-degree family members. For example, the proposed definitions include grandparents, great-grandparents, and great-great grandparents among second-, third- and fourth-degree family members, respectively. AARP supports these thoughtful definitions, which are important in understanding the reach of prohibitions on use of genetic test results on family members.

Genetic information: The IFR establishes, consistent with the requirements of Title I of GINA, greater consistency between the definition of genetic information in GINA and the 2004 final HIPAA portability regulations. We support these clear definitions of "genetic services" and "genetic tests," which are both important to the application of the Title I requirements.

Manifestation or Manifested: Similarly, we support the definitions of these key terms, which bring clarity for purposes of insurer and group health compliance and agency enforcement. These workable definitions are critical for applying GINA's protections against genetic based discrimination.

Health Risk Assessments

We agree with the IFR that, if employers use genetic information from an HRA to determine premium discounts, rebates or incentives or to increase cost-sharing, then the employer is using genetic information to underwrite in violation of GINA. We strongly support workplace wellness programs, which have great potential to improve health and decrease costs. However, these programs should not become a backdoor to discrimination based on genetics or other health status factors. We agree that the law permits employers to use HRAs only if they do not request or require genetic information or link completion to rewards, discounts or decreased cost sharing obligations. AARP believes the IFR gives insurers and group health plans sufficient flexibility to use HRAs to provide incentives to employees to participate in disease management and other wellness programs while still protecting the privacy of the genetic information of program participants.

Determination Regarding Payment

We recognize the rationale for the IFR provision allowing plans to use genetic information when -- and only when -- an individual patient's genetic make-up is necessary to determine if payment for an item or service is medically appropriate. However, we urge vigilant oversight to ensure that this appropriately narrow exception is not misused to improperly collect genetic information for other reasons.

We hope that these comments are helpful. If you have any questions, please contact Paul Cotton on our Government Relations team at (202) 434-3770.

Sincerely,

David Certner
Legislative Counsel and Legislative Policy Director
Government Relations and Advocacy