New Regulations Prohibit Questions Regarding Family History or Other Genetic Information on Certain Health Risk Assessments

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Practice Area: Health Industry Labor, Employment and Immigration & Compensation and Benefits/ERISA & Labor and Employment

On October 7, 2009, Interim Final Rules were issued to implement certain sections of the Genetic Information Nondiscrimination Act ("GINA"). These rules prohibit (i) the use of genetic information for increasing the group premiums or contribution amounts based on genetic information; (ii) requesting an individual or family member to undergo genetic testing, except in limited circumstances; or (iii) requesting genetic information in connection with enrollment or for "underwriting purposes," which includes offering benefits or rewards for completing a health risk assessment ("HRA").

The rules, which apply to group health plans and group insurance issuers for plan years beginning on or after December 7, 2009, seek to prevent discrimination and underwriting based on genetic information. "Genetic information" includes not only results of a covered individual's genetic test, but also genetic tests of family members of the individual and the manifestation of a disease or disorder in family members of the individual. Note that information relating to an individual's own medical history, aside from the results of genetic tests, is not considered "genetic information." The rules broadly define "underwriting" to include not only determining eligibility and applying pre-existing condition exclusions, but also setting premiums and deductibles. The rules prohibit collecting genetic information, including family medical history, before or in connection with enrollment or at any time if done in connection with a reward or incentive, such as lower premiums, deductibles, or co-payments.

Requesting Genetic Information in Exchange for Lower Premiums or Other Reward Not Allowed

If an HRA includes questions regarding family medical history or other genetic information, it may violate the new rules. Such an HRA could be administered after enrollment if it is not connected to any benefit or reward. If, however, the HRA is administered before or during enrollment, or if a premium reduction or other reward is given for participation, it will violate the new rules.

Previously, incentives could be given for participation in an HRA, provided the results of the HRA were not used to discriminate against any employees based on a health factor. Incentives still may be provided if the HRA does not include any questions regarding family medical history or other genetic information.

If an HRA currently includes questions regarding family medical history or other genetic information, no incentive or reward should be offered for completion, and the HRA should be completed after enrollment. If an employer or plan would like to continue to offer an incentive or reward for completing an HRA, any questions relating to an individual's genetic information or family medical history should be removed. These questions could be separated out into a different questionnaire expressly stating that it is not tied to enrollment or any reward.

If an HRA includes open ended questions that could reasonably cause people to respond with information as to family medical history or other genetic information, a clear caveat should be included explicitly stating that individuals should not provide genetic information when responding to the question.

Eligibility for Disease Management Programs Should Not be Determined from Family History Provided in an HRA

In addition, procedures for participant enrollment in disease management programs offered by group health plans may need to be revised. Any disease management programs that condition enrollment on an individual's own manifestation of a particular disease may continue to operate as they have in the past, because they do not rely on genetic information to determine eligibility. However, health plans that use the results of family history questions on an HRA to determine eligibility for enrollment must revise their enrollment procedures. The use of family history questions on an HRA to determine eligibility for enrollment in a disease management program is considered under the regulations to be an impermissible use of genetic information to determine access to benefits. Instead of using an HRA to determine who may enroll in a disease management program, health plans must offer the program to all similarly situated participants and allow participants who wish to participate to provide information to the health plan to prove their eligibility for the program.

For example, if a health plan offers a diabetes management program to all individuals for whom it is medically appropriate (based on an individual either having or being at risk for diabetes), the plan may send out a notice to all participants explaining the terms for eligibility for the program. Individuals who wish to enroll in the program based on their risk of developing the disease may contact the health plan to demonstrate that they are at risk for developing diabetes. Individuals may demonstrate their risk, for example, by showing that a family member has diabetes. The regulations allow the health plan to collect genetic information for the purpose of determining whether the disease management program is medically appropriate for those individuals.

Other Medical Inquiries or Questionnaires

Although these particular rules govern only health care-related inquiries, other sections of GINA generally prohibit employers from acquiring genetic information. The EEOC has issued proposed rules, which are expected to be finalized before the November 21, 2009 effective date of GINA, that prohibit employers from asking questions about family history or other genetic information on post-offer and fitness for duty medical examinations or inquiries. Like in the HRA described above, questions about family medical history should be removed from postoffer and other medical questionnaires or examinations.

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