



# GINA: THE GENETIC INFORMATION NONDISCRIMINATION ACT

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## HOW IT IMPACTS EMPLOYERS AND HEALTH PLAN ISSUERS USING HEALTH RISK ASSESSMENTS

On November 21, 2009, provisions of the Genetic Information Nondiscrimination Act (GINA) of 2008 went into effect for all employers. Federal regulations applicable to health plan issuers and employer-sponsored group health plans became effective December 7, 2009. This law restricts the commonly used practice of offering incentives to complete a health risk assessment (HRA) in connection with a group health plan. The Act also prohibits employers from requesting genetic information from employees, and limits who can receive family health history responses submitted through an HRA to licensed healthcare professionals.

This white paper is meant to assist you in understanding the basics of GINA and the regulations, how they impact the use of HRAs in your wellness program, and what you can do to easily modify your program to keep it in legal compliance using Wellsource® health risk assessment tools.

## OVERVIEW OF GINA

GINA protects U.S. citizens against discrimination in health coverage and in employment based on their “genetic information.” Family medical history,<sup>1</sup> which qualifies as genetic information, has traditionally been a component of most health risk assessments, including those developed by Wellsource.

GINA is divided into two different sections, or Titles. Title I of GINA prohibits discrimination based on genetic information in **health coverage**.<sup>2</sup> Health plan issuers and group health plans sponsored by private employers are subject to Title I. Title I of GINA became effective for plan years beginning after May 21, 2009, and on January 1, 2010 for calendar year plans. The regulations interpreting Title I of GINA become applicable the first day of the plan year on or following December 7, 2009.

Title II of GINA prohibits discrimination based on genetic information in **employment**, and went into effect for all U.S. employers on November 21, 2009. Employers offering HRAs to their employees as part of a wellness program that is **not** connected in any way to a group health plan are subject to Title II of GINA. Interpretive rules have been issued by the EEOC.

### Key Points of GINA:

- ✓ Restricts the commonly used practice of offering incentives to complete a health risk assessment (HRA) in connection with a group health plan
- ✓ Prohibits employers from requesting genetic information from employees
- ✓ Limits who can receive family health history responses submitted through an HRA to licensed healthcare professionals

## TITLE I'S EFFECT ON INCENTIVES

The regulations relating to Title I of GINA prohibit the use, collection,<sup>3</sup> and disclosure of genetic information by covered health plans for “underwriting purposes,” which is defined broadly to encompass determinations of eligibility for benefits (including enrollment and continued eligibility), computation of premium or contribution amounts, changing deductibles or other cost-sharing mechanisms, and providing discounts, rebates, or other benefits. “Covered health plans” include issuers as well as group health plans sponsored by private employers.

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*1 “Family medical history” is defined as information about the manifestation of disease or disorder in family members of the individual, but does not include information about a person’s age or sex.*

*2 Group health plans that have fewer than 2 participants who are current employees are exempt.*

*3 “Collect” means to request, require, or purchase such information. So even asking the question will be unlawful under GINA.*

As a result, enrollment in a group health plan can no longer be conditioned upon completion of an HRA that requests genetic information such as family health history. Moreover, questions eliciting genetic information need to be eliminated from the HRA in most cases to be able to offer incentives, such as reduced premiums or other rewards for completing the HRA. This is true even if the rewards are not based on the outcome of the assessment and would otherwise meet the HIPAA nondiscrimination rules for wellness programs.

### **Going forward, covered health plans will only be able to ask about family history in an HRA when the following two conditions are met:**

1. No incentive or benefit of any kind is offered in exchange for completing the HRA,<sup>4</sup> AND
2. The HRA is offered after the enrollment period has passed (not prior to or in connection with enrollment in a health plan).

The easiest way for health plans and employers to comply with GINA and retain the ability to offer incentives in conjunction with HRAs is to simply remove questions pertaining to family medical history. The online versions of PWP Concise, Comprehensive, and Advantage all have the ability to “hide” the family health history question. Contact Wellsource Technical Support at 503-557-0373, visit the technical support page of our website, or email [techsupport@wellsource.com](mailto:techsupport@wellsource.com) to learn how. Paper questionnaires without the family health history question are also available for ordering.

## **TITLE II'S PROHIBITION ON EMPLOYER ACCESS TO GENETIC INFORMATION**

Employers offering an HRA as part of a corporate wellness program where participation is **not** tied to the group health plan in any way (i.e., by offering a reduction in premiums or requiring completion of the HRA prior to joining the plan) are subject to Title II of GINA. Title II prohibits use of genetic information in employment decision-making, restricts the deliberate acquisition of genetic information by employers, and requires that genetic information be kept confidential. Employers are no longer permitted to obtain **any** genetic information from employees,<sup>5</sup> including family health history collected through an HRA, unless a qualified exception applies.

The most notable exception is for wellness programs, although strict conditions apply. GINA permits employers to implement wellness programs that collect family medical history, provided:

1. Participation is not required and employees are not penalized in any way for not participating.
2. The individual provides prior knowing, voluntary, and written consent.
3. Individually identifiable genetic information (such as responses to family medical history questions in an HRA) may only be provided to the individual from whom it was obtained and the “licensed health care professional”<sup>6</sup> or “board certified genetic counselor” involved in providing such services; and
4. Any individually identifiable genetic information provided is only available for purposes of such wellness services and is not disclosed to the employer except in aggregate terms that do not disclose the identity of specific individuals.<sup>7</sup>

Organizations with existing online sites who want to continue to ask family health history questions under the wellness exception should contact Heather Tourville, General Counsel for Wellsource, at [heather@wellsource.com](mailto:heather@wellsource.com) to amend their online Terms & Conditions page to address these requirements.

In summary, if no qualifying third party wellness provider is engaged by the employer and HRA results are being received directly by a wellness program administrator who does not qualify as a “licensed healthcare professional,” the family health history question must be omitted from the HRA. Even asking the question will be unlawful under GINA, regardless of whether a response is provided. No personally identifiable genetic information at all can be viewed by the employer (even with the employee’s consent). Previously collected data is exempt; however, genetic information collected prior to the date of GINA cannot be used to discriminate against an individual in health coverage or employment.

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<sup>4</sup> There is no de minimus exception to the award prohibition. In other words, the regulations do not provide an exception for rewards provided by wellness programs, regardless of the amount of the award.

<sup>5</sup> The term “employee” includes applicants and former employees.

<sup>6</sup> “Licensed health care professional” is not a defined term, however the regulations state it is not limited to physicians.

<sup>7</sup> However, a covered entity that receives aggregate information may still violate GINA where the small number of participants, alone or in conjunction with other factors, makes an individual’s genetic information readily identifiable. Generally, this requires more than 50 in the group results.



## Healthcare Providers Not Inhibited by GINA

Healthcare professionals who are providing health care services to an individual may continue to collect genetic information, including the person's family medical history. However, the regulations stipulate that "[t]he health care professional must actually be providing health care services to the individual for the exception to apply."

## HOW WILL ELIMINATING FAMILY HEALTH HISTORY IMPACT SCORING ON THE ASSESSMENT?

Family health history has traditionally been a component of risk computation in Wellsource<sup>®</sup> health assessments. However, family health history can be omitted from the Personal Wellness Profile<sup>™</sup> (PWP) questionnaire for clients prohibited from collecting this data going forward, with minimal impact on scoring. If no family history is collected, the PWP Personal Report will treat the lack of data as if the participant had no family history of the risk, in effect minimizing risk slightly.

For PWP Concise and Comprehensive users, individual risk scores (i.e., the cancer risk score) will be slightly impacted. However, whether changes in the individual risk scores will affect the person's overall wellness score depends on the built-in break points for that score (not all individual risk scores will affect the overall wellness score).

For PWP Advantage users, the lack of data on family health history will have even less of an impact on scoring. The family history risk factors in Advantage only add one point to the individual risk scores; personal health history, clinical results, and other risks also impact the risk score. So the effect on individual risk scores will be to lower that score by a value of 1. The overall wellness score will not be affected in Advantage by hiding the family health history question.

The Personal Report language for PWP Advantage has been modified to inform participants that a history of certain diseases in the family may impact the individual's risk of developing the same disease. In the Personal Report for PWP Concise and Comprehensive, hereditary risks will simply remain unchecked as a risk factor that does not apply; the actual report language does not change.

For more information on scoring methodology in any of the PWP reports, please contact Dr. Gerard McLane at [drmclane@wellsource.com](mailto:drmclane@wellsource.com) or 503-656-7446 ext. 224.

## HOW DO I "HIDE" QUESTIONS REGARDING GENETIC INFORMATION OR ORDER MODIFIED PAPER ASSESSMENTS?

The only question in the Personal Wellness Profile<sup>™</sup> that asks for genetic information is the family health history question. This is question #1 on the PWP Comprehensive questionnaire, and question #3 on the PWP Advantage and Concise questionnaires.

Clients may configure the online PWP (Concise, Comprehensive, and Advantage) to be GINA-compliant by hiding the family health history question. Contact Wellsource Technical Support at 503-557-0373, visit the technical support page of our website, or email [techsupport@wellsource.com](mailto:techsupport@wellsource.com) to learn how. New deployments are set to hide family health history questions by default.

To offer GINA-compliant paper HRAs, Wellsource stocks PWP Advantage, Concise, and Comprehensive paper questionnaires in two versions:

1. Family health history question marked as optional (for healthcare providers who want to continue to collect the data), or
2. Family health history omitted.

Clients who have questionnaires on hand that ask about family history can amend them in the following manner to be GINA-compliant:

- a. White Avery® labels<sup>8</sup> can be placed over the question (including the bubbles). Modified questionnaires will still scan and give a valid report.
- b. A black marker may be used to line out the questions only. *Clients must not mark over the bubble* as doing so will cause it to read as a positive response.

Wellsource is unable to accept the return of unused forms in exchange for new ones.

### Recommended Modifications for Wellness Programs

Consult with your legal counsel in advance of the start of your new plan year if you have traditionally given incentives for completion of an HRA prior to or in connection with a group health plan. In this scenario, rewards should only be offered for completing HRAs that do not request any genetic information like family health history.

Beginning November 21, 2009, if HRA results are being received directly by a wellness program administrator who does **not** qualify as a “licensed healthcare professional,” the family health history question must be omitted from the HRA.

GINA’s provisions run up against, and in some cases amend, other major federal laws like ERISA, HIPAA, the ADA, and others. Although this white paper pertains only to the newly enacted federal GINA law, it should be noted that over 40 states also have laws addressing genetic discrimination in employment. Some may be more stringent than GINA — others less so. Wellness coordinators must be diligent in staying informed of applicable state laws as well, since the more protective law will apply.

For more detailed information on how the law applies specifically to your organization, you are advised to consult your legal department or outside legal counsel.

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*8 5162 or 8162 (1-1/3" x 4") for PWP Advantage; 5163 or 8163 (2" x 4") for PWP Concise; and 6874 (3" x 3-3/4") for PWP Comprehensive.*



#### About the Author

Heather Tourville, J.D., is General Counsel for Wellsource, Inc. A managing team member since coming to Wellsource in 2004, Heather facilitates business transactions on behalf of Wellsource, oversees general operations, and handles legal compliance issues. Heather is an active member of the Oregon State Bar.



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