

ASHG opposes revised EEOC regulations weakening genetic privacy

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The American Society of Human Genetics (ASHG) opposes the U.S. Equal Employment Opportunity Commission's (EEOC) newly revised Regulations under the Americans with Disabilities Act (ADA) and under the Genetic Information Nondiscrimination Act (GINA).

"These revisions will significantly weaken the patient privacy protections in the ADA and GINA," said Derek T. Scholes, PhD, ASHG Director of Science Policy. ASHG played a key role in the inception of GINA and supported the law's passage in 2008.

A key component of ADA and GINA is that they prevent workers and their families from being coerced into sharing sensitive medical or [genetic information](#) with their employer. For GINA, genetic information encompasses not only employees' genetic test results but also their family medical histories. According to a [2007 Senate report on GINA](#), Congress explicitly crafted the law to include spouses' medical histories to prevent employers from discriminating against employees because of the potential costs of their spouses' medical care.

ADA and GINA do allow employer-sponsored wellness programs to request medical or genetic information, but require that employee participation in such programs be entirely voluntary. Per the Senate report on GINA, Congress incorporated this wellness program provision so employees could take advantage of opportunities to improve their health without fear of workplace discrimination.

Under the final rules issued today, however, employers can require that employees who choose to keep their and their spouses' [health information](#) private pay significantly higher health insurance premiums. For plans that cover both the employee and the spouse, the employee could be required to pay a per-person penalty of up to 30 percent of the cost of self-only coverage. Given that the average cost of a self-only plan is \$6,251 per year, the new rules would allow an employer offering such a plan to impose an annual \$3,750 penalty for an employee and his or her spouse.

"The new EEOC rules mean that Americans could be forced to choose between access to affordable healthcare and keeping their health information private," said Dr. Scholes. "Employers now have the green light to coerce employees into providing their health information and that of their spouse, which in turn reveals genetic information about their children."

"One of the main reasons for enacting GINA was to reassure people that they could participate in medical research without employers gaining access to their genetic information," Dr. Scholes added. "So it is especially unfortunate that these regulatory changes coincide with the launch of the largest-ever genetics experiment in the United States, the Precision Medicine Initiative, which will provide participants access to their study results. People may choose not to participate out of fear that they will be coerced into reporting these results to their employers' wellness programs."

More information: Kaiser Family Foundation. (2015 Sept 22). [2015 Employer Health Benefits Survey](#).

U.S. Federal Register. (2016 May 17). [Regulations under the Americans with Disabilities Act](#). Document No. 2016-11558.

U.S. Federal Register. (2016 May 17). [Genetic Information Nondiscrimination Act](#). Document No. 2016-11557.

U.S. Senate. (2007 April 10). [Report 110-48: Genetic Information Nondiscrimination Act of 2007](#).

Provided by American Society of Human Genetics

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