GINA, Genetic Discrimination, and Genomic Medicine

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In 2008, after 13 years of advocacy by the genetics community and U.S. lawmakers, the Genetic Information Nondiscrimination Act (GINA) was signed into law. GINA is the first U.S. federal antidiscrimination statute crafted to address an area where there was no well-documented history of widespread discrimination and no stigmatized group to protect. The statute’s language is unusual, proposing not only “to fully protect the public from discrimination” but also to “allay their concerns about the potential for discrimination, thereby allowing individuals to take advantage of genetic testing, technologies, research and new therapies.”

GINA was initially lauded as a huge legislative success, though some critics argued that it didn’t go far enough in providing comprehensive protection. For example, GINA defined genetic information to include genetic test results and family history but excluded from its protections people with manifest disease. This exclusion established a legislative gap between employment protections afforded by GINA for asymptomatic people, as well as those offered by the Americans with Disabilities Act (ADA) for people with substantially limiting impairments. People with manifest disease who are not yet disabled were left unprotected. In addition, whereas GINA prohibits discrimination in employment and health insurance, it does not address life, disability, or long-term care insurance. And it does not apply to employers with fewer than 15 employees or to the U.S. military, the TRICARE military health system, the Indian Health Service, the Veterans Health Administration, or the Federal Employees Health Benefits Program, though other policies protect people in those programs.

Has GINA nevertheless succeeded in its twin missions of preventing discrimination and alleviating public fears about the potential for discrimination? That’s a difficult question to answer. In the past 6 years, genetic testing has dramatically increased, yet there have been very few cases of discrimination in which GINA’s authority could be tested. The Equal Employment Opportunity Commission (EEOC) estimates that in fiscal year 2013 there were 333 GINA-related charges of
Employment discrimination (vs. more than 90,000 in other areas), and most of them also included ADA-related claims. In some cases, according to Peggy Mastroianni of the EEOC, the GINA claim was added only after the investigation of an ADA charge uncovered evidence that an employer had asked about an employee’s family history.

Although GINA does not explicitly prohibit discrimination in

Fear of discrimination may be preventing some people from participating in translational research studies that are exploring the real-world consequences of utilizing genomic information, with its potential for unanticipated or incidental findings.

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Using Drugs to Discriminate — Adverse Selection in the Insurance Marketplace

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Eliminating discrimination on the basis of preexisting conditions is one of the central features of the Affordable Care Act (ACA). Before the legislation was passed, insurers in the nongroup market regularly charged high premiums to people with chronic conditions or denied them coverage entirely. To address these problems, the ACA instituted age-adjusted community rating for health insurance but more acceptable to discriminate for products such as life, disability, and long-term care insurance. In defending the right to such discriminatory underwriting, insurers have claimed that if applicants have relevant information that isn’t available to insurers, such as robust genetic risk information, low-risk consumers will drop out of the mix and higher-risk consumers will disproportionately purchase coverage, forcing companies to raise prices and causing a “death spiral” of adverse selection.

This concern was largely theoretical until we showed that healthy people with higher-risk results on predictive genetic testing were more likely to use that information to make decisions about purchasing long-term care insurance. If this finding is generalizable, then for insurance products that remain outside GINA’s scope, the status quo is unlikely to last. As more people obtain their own genetic risk information, companies selling such products may feel forced to test customers genetically in order to stratify customer risk. Alternatively, we may eventually have to abandon risk-based underwriting and adopt a more unitary pricing system that pools risk. The standard argument for regulating risk classification is that it’s unfair for employers to discriminate or insurers to charge different rates because of immutable risks. GINA’s exceptionalism may, in part, reflect a genetic determinism and therapeutic nihilism that were prevalent in 1995, when Congress first considered this issue, but that will be far less salient in the future. Although genetic determinism with regard to highly penetrant mendelian conditions may persist, it’s now clear that everyone carries genetic variants that will influence, but in most cases not exclusively determine, one’s health status. The science of genomic medicine is moving rapidly toward multiscale network and systems biology by elucidating the complex interactions of genomics, physiology, and environmental influences. In a future informed by this science, we may be able to personalize risk stratification and then tailor diet, exercise, and pharmaceuticals and even edit genes to promote wellness by preventing and minimizing illness. Eventually, the notion of immutable genetic risks may become obsolete, and it may be less important to grant genetic information special protection than to protect everyone from all forms of medical discrimination. As all medicine in a sense becomes genomic medicine, perhaps the genetic nondiscrimination secured by GINA will translate into nondiscrimination in all of medicine.

Disclosure forms provided by the authors are available with the full text of this article at NEJM.org.

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