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European Practices of Genetic Information and Insurance

Lessons for the Genetic Information Nondiscrimination Act

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ONE OF THE MOST CONTENTIOUS TOPICS IN PUBLIC policy debates on genetics has been the use of genetic information by insurance companies. In the rush to confront concerns about potential misuses of genetic information, most European countries have since 1990 enacted genetic nondiscrimination legislation for life or health insurance. In the United States, the Genetic Information Nondiscrimination Act (GINA) was recently signed into law to provide protection against genetic discrimination for employment and health insurance.^{1,2}

In US public opinion surveys over the years, an increasing majority of respondents have indicated a desire for legislation such as GINA.³ Advocates of the bill claim that many individuals defer having genetic tests performed—for instance, to detect a mutation that increases risk of breast cancer—for fear that insurers or employers will discriminate against them based on that information. The threat of genetic discrimination has also hindered medical research; according to Collins, “Unless Americans are convinced that the information will not be used against them, the era of personalized medicine will never come to pass.”⁴

These fears also seem to disrupt health care delivery. To keep genetic information out of their medical records and out of the hands of insurers, patients sometimes refuse genetic testing that could benefit their health; they also sometimes pay out of pocket or use assumed names to keep the information private. The intentions of enacting GINA are clear: genetic discrimination in consideration for insurance and employment will be banned by federal legal mandate. The act should help alleviate public fear of genetic discrimination, enabling the progress of genetic research and preventive health or use of genetics in clinical care.

The European Experience

In this instance, Europe may be ahead of the United States in experience. In Europe, genetic nondiscrimination legis-

lation was introduced beginning in 1990 in Belgium, and many European countries have followed. This European experience has enabled the study of practical effects of these laws in insurance practice. An outline of how these laws have worked, based on document analysis, in-depth observations, and interviews concerning the practices of genetic nondiscrimination legislation in insurance, is provided below. European experience highlights some concerns and problems these laws may bring about.

One concern is whether genetic nondiscrimination legislation in Europe has been effective. European experience demonstrates how the effects of this legislation may be more complex than expected. Although no current evidence exists to suggest increased genetic discrimination after the European laws' enactments, these laws have not seemed to prevent genetic information from being used in insurance practices.⁵ For instance, despite a national legal ban on the use of genetic information, medical advisors and underwriters in Belgian insurance companies still may use genetic test results or genetic information derived from physician records or insurance questionnaires. Often this arises from ignorance, confusion, or misunderstanding of genetic conditions in the context of insurance underwriting. However, it also is due to the lack of clear definitions of “genetic data” or “genetic tests” in the laws.⁶ Therefore, the boundary between “genetic” and “nongenetic” data are not always distinct in insurance practices.

It seems that these laws have not always delivered on their promises. Moreover, some of the laws' definitions seem to be outdated, given the recent progress in genomics knowledge. It is increasingly acknowledged that the distinction between genetic and nongenetic information is quite artificial.⁷ New developments in genomics complicate legal concepts and distinctions. The original scope of protection provided by most European laws has been narrow. For example, some laws exclude chemical tests, blood tests, and routine

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laboratory tests from the definition of genetic tests. Given that all genetic tests are chemical tests, many are blood tests, and an increasing number are routine, many European laws provide only the illusion of protection.

Much confusion exists in the application of these genetic nondiscrimination laws by insurance companies. For many insurance company medical advisors, it is difficult to maintain the original legal distinction between genetic and nongenetic information. Medical advisors also use indirect forms of genetic testing, such as genetic information derived from chromosomes or proteins or obtained via routine urine or blood tests. This confusion raises questions regarding the “survival time” of the GINA laws and highlights a continuous tension between legal definitions and dynamic genomics practice.

These laws may have difficulties for preventing the public fear of genetic discrimination. European experience indicates how even after regulatory actions, individuals may still fear genetic discrimination, resulting in withdrawal from genetic research and clinical care.⁸ Even with legislation, many individuals do not trust insurance companies and other institutions on delicate issues such as their use of genetic information. This latent mistrust makes it even more important for legislation to deliver on its promises.

Unintended Effects

European experience demonstrates that genetic nondiscrimination laws create some unintended effects. While the legislative focus has been on the unacceptability of genetic discrimination, other possible discrimination in insurance practices have arisen.⁹ Smokers, obese individuals, and individuals who do not comply with prescribed therapy are confronted with sharply increased prices and possibly with exclusion from insurance coverage.¹⁰⁻¹³ The exclusive legal protection of genetic risks has occurred with an increasing discrimination against lifestyle risks.¹⁴ By providing exclusive legal protection to the group with genetic risks, groups with other nongenetic risks are unintendedly left relatively underprotected. Lifestyle risks are disproportionately disadvantaged by laws that protect against discrimination based exclusively on genetic risks. This may result in inequities between similarly situated individuals. Genetic nondiscrimination laws raise new issues with respect to responsibility for health risks in insurance and stimulate reflection on the question “who deserves our solidarity?”¹⁵

Based on these European experiences, GINA may offer great promise—but it also introduces new risks. While in-

tended to solve the issue of genetic discrimination, the act actually may stimulate new issues of discrimination. As the practices of European insurance and genetics suggest, this type of legislation may not completely do what is intended and may cause unintended consequences. These lessons need to be taken into account before embracing GINA. The limitations and potential downsides that may accompany genetic nondiscrimination legislation should be considered carefully.

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