Genetic testing and insurance implications: Surveying the US general population about discrimination concerns and knowledge of the Genetic Information Nondiscrimination Act (GINA)

Anya E.R. Prince, JD, MPP*[1], Wendy R. Uhlmann, MS, CGC[2], Sonia M. Suter, JD, MS[3], & Aaron M. Scherer, PhD[4]

Executive Summary

Anya E.R. Prince

In 2008, the United States Congress passed the Genetic Information Nondiscrimination Act (GINA), which prohibits covered health insurers and employers from discriminating against individuals on the basis of genetic information. Over the last few years, several other prominent policies that minimize insurer access to genetic test results during underwriting have been enacted or adopted. For example, the Canadian Parliament passed the Genetic Nondiscrimination Act in 2017, making it a criminal offense to consider genetic information when making insurance contracts. In 2019, the Australian Financial Services Council adopted a moratorium for life insurance policies below AU$500,000. While these are some of the latest examples, they by no means stand alone. One worldwide review of genetic antidiscrimination rules regarding insurance found relevant policies in 47 countries.

Although GINA has been on the books for over a decade, research has shown that knowledge of the law is low among patient populations and healthcare professionals. Few studies have looked in-depth at knowledge of GINA in the general population. To fill this gap, we conducted two surveys of the general US population in April and July 2020. In this Shin Research Paper, we combined the responses from the two surveys to analyze whether respondents' occupation, history of genetic testing and/or genetic conditions, and insurance status were correlated with subjective and objective knowledge of GINA.

We utilized Qualtrics Research Services to survey US adult residents in the general population, utilizing sampling quotas so our survey population closely mirrored the general US population for gender, age, race, ethnicity, educational attainment, and total household income. We used Stata to analyze descriptive statistics and test for significant bivariate correlations, differences in means using t-tests and ANOVAs, and multiple regression analyses.

[1] University of Iowa College of Law
[2] Department of Internal Medicine, Division of Genetic Medicine; Department of Human Genetics; Center for Bioethics and Social Sciences in Medicine, University of Michigan School of Medicine
[3] The George Washington University Law School
[4] Department of Internal Medicine, University of Iowa

Overall, the surveys showed that knowledge of GINA continues to be very low in the general US population. More than 75% of the respondents reported that they had low or moderate subjective familiarity with GINA. Even among those who reported high subjective familiarity, only approximately 60% correctly indicated that GINA covers health insurance and employment and more than half incorrectly believed that GINA protects in the realms of life, long-term care, disability, auto, or property insurance.

When we specifically analyzed our key subpopulations of interest (occupation, genetic testing status, and insurance status), we found several bivariate findings. However, these findings should be taken with a grain of salt, since our subsequent multivariate analysis did not unearth many statistically significant findings. This indicates that bivariate analysis results could be driven by other factors outside these subpopulations, like age, education, or an unmeasured characteristic.

For occupation, we found that those working in science, health, and law had higher subjective familiarity of the law than their counterparts not working in the fields. However, these groups did not have higher objective knowledge.

For genetic testing history we found that those who had undergone direct-to-consumer genetic testing, had completed a genetic test (diagnostic, predictive, carrier, or prenatal), and had a genetic condition in themselves or their family, had both higher objective and subjective familiarity of GINA than their counterparts. However, when genetic testing was broken down further, those who had completed predictive genetic testing had higher subjective familiarity, but not higher objective knowledge of the law.

For insurance status, those who had been denied insurance in the past due to a medical condition and those who had individual and group health insurance had higher subjective and objective knowledge of GINA than those without insurance denials and those without insurance.

Notably, however, when we ran multivariate regression models that included the demographic variables of occupation, genetic testing history, insurance status, gender, race and ethnicity, age, income, and education, most findings from the bivariate analysis were not found to be statistically significant. Of the subpopulation demographics, only being offered genetic testing was associated with higher subjective familiarity of GINA and none of these demographics were associated with higher objective knowledge of the law.

While this paper focuses on GINA and the US, it provides insight into the global debate over insurer use of genetic information. Key arguments on both sides of the debate rest on the extent to which individuals are aware of and knowledgeable of policies regarding insurer use of genetic information. For example, proponents of a ban on insurer use of genetic information argue that barring such use has the potential to save lives because evidence has shown that some individuals fail to get medically necessary, preventive genetic testing out of fear of

discrimination in life or other insurances. However, if the public is not aware of laws that prohibit discrimination, their fears are unlikely to be assuaged.

Similarly, insurers argue that the inability to underwrite on the basis of genetic information could lead to increased premiums and instability in the market due to potential for anti-selection. However, anti-selection depends, in part, on the extent to which individuals who test positive for genetic risk try to 'game the system' and purchase high levels of insurance at lower premium rates. However, realization of this worry requires applicants to have some knowledge of the system they are gaming.

Our survey results show that individuals generally are unaware of legal protections in the US and, even when they are familiar with the law, are often confused about the specific protections. While we did find some subpopulations with relatively higher knowledge of GINA in bivariate analysis, the overall rates were still low and these results did not hold in multivariate analysis.

In many ways, the debate over insurer use of genetic information is a question of balance. Specifically, do potential public health and antidiscrimination benefits on a bar of insurer use of genetic information outweigh any potential economic impact on the insurance industry and premiums? To answer this question, it is important to understand how much laws regulating insurer use of genetic information impact two types of public behavior: insurance purchasing behavior and uptake of predictive testing and prevention. Our study begins to empirically explore this through examination of knowledge of US genetic antidiscrimination law. Future studies should continue to unravel the complex interactions between knowledge of legal protections, concerns of genetic discrimination, and other important factors, such as trust of the insurance industry, both in the US and abroad.