

How State and Federal Laws Are Addressing the Use of Direct-to-Consumer Genetic Testing by Insurance Companies

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While life insurers traditionally have set premiums based on a multitude of complex actuarial tables, the recent boom in direct-to-consumer DNA testing products, such as 23andMe and AncestryDNA, is expanding the universe of genetic information available about consumers for consideration in rate-setting and other underwriting and policy operations.

Many of the genetic testing products on the market provide not only information about consumers' ancestry, but also about predispositions to diseases by revealing genetic variants associated with an increased risk of developing certain health conditions, such as Parkinson's. Insurance industry experts fear that the increased adoption and use of genetic testing may pose a threat to the industry should customers buy policies knowing, but not disclosing, genetic predispositions to certain disorders. On the other hand, many consumers fear that such information may be used to discriminate against them in the underwriting process.

Federal and state legislatures are taking active steps to regulate the use of genetic information by insurers. For example, the Federal Genetic Information Nondiscrimination Act of 2008 (GINA) makes it illegal for health insurers to request, require, or use consumers' genetic information to make decisions about eligibility for health insurance or the health insurance premium, contribution amounts, or coverage terms. Notably, these protections do not apply to long-term care policies, life insurance, or disability insurance; however, some states have adopted similar laws that address life insurers.

As of June 2018, 17 states have laws restricting life insurers from using genetic information in their underwriting process. In addition, several of these states – for example, California, through its Genetic Information Nondiscrimination Act (CalGINA) – extend protections even further to prohibit genetic discrimination in emergency medical services, housing, mortgage lending, education, and other state-funded programs. As states continue to adopt consumer protection laws related to genetic information, it remains to be seen how the insurance industry will adapt, and whether, and in what form, genetic testing will become a part of their risk assessments.