S. 247 – Access to Genetic Information for Life Insurance Companies

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Introduction

S.247, intended to prohibit discrimination based on genetic information, builds upon the protections within 18 V.S.A. § 9334 and the Genetic Information Nondiscrimination Act of 2008 (GINA) by better defending the privacy of life insurance policy owners. Vermont requires individuals who seek a genetic test to sign a written informed consent form that includes information on the risk of non-health insurance discrimination. S.247 follows in form with legislatures across the country – Florida, Colorado, Maine, and Illinois, who have taken action to protect individual policyholders.

For insurance companies, there is adverse selection risk – an individual policyholder could get a direct-to-consumer genetic test, discover their predisposition to a certain disease or illness, and withhold that information, to remain paying a low premium. As consequence, the life insurance company must incur the cost if the individual policyholder dies. It is argued, then, insurance companies should have access to this information to ensure, these companies will not make bad investments, therefore, stay solvent. Insurance companies, if given access to genetic information, could lower an individual policyholder's premium payment amount, if, say, they had assumed they were at great risk for an illness or disease, but a genetic test uncovers they are not since they do not carry the genetic potential. Insurance companies argue, as genome sequencing becomes more commonplace, no longer will there be outliers who have granted access to this information – when this occurs, everyone will be treated equally.

The main concern of individual policyholders is insurance companies will be discriminatory if they have access to genetic information – more specifically, a test could provide information that could cause an insurer to decline to provide service if an individual has genetic markers in their genome. There are also evident flaws in the direct-to-consumer genetic tests many individual policyholders choose to use. A study conducted in 2018 by Genetics in Medicine found 40% of gene variants identified by athome consumer tests were false positives. Those gene variants that indicated “increased risk” to the genetic test direct-to-consumer companies, were found later to be benign risk in clinical laboratories[1]. It is salient to note genetic tests do not indicate an individual’s predisposition to conditions, but only as a diagnostic tool or if there is a blood relative’s history of disease.

Vermont – S.247

S.247 defines genetic information as, the results of genetic testing related to an individual or a family member of the individual contained in any report, interpretation, evaluation, or other record. The act prohibits life insurance companies from accessing an individual’s genetic information if the information has not led to a diagnosis. The act also prohibits life insurance companies from accessing the genetic information of an individual’s blood relatives if the information has not led to a diagnosis. The market for long-term and life insurance policy in Vermont is challenging currently, says Deputy Commissioner Kevin Gaffney, of the Department of Financial Regulation Vermont in testimony.

Florida – HB.1189

H.1189, titled Genetic Information for Insurance Purposes, was passed July 1, 2020, and is the best comparison to S.247 in what it seeks to accomplish. The bill defines genetic information similarly to Vermont – genetic information is information derived from genetic testing, not including information from testing from routine physical examinations or chemical, blood, urine unless conducted to obtain genetic information regarding family history. The summary report produced by Florida House Commerce Committee, the main justification for the passage of the bill was concerns over third-party use of genetic information[2]. The bill is an extension of a previous bill that had disallowed health insurers from accessing genetic information but had not done the same for long-term care and life insurance. As passed, the bill contains an

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[1] https://www.forbes.com/advisor/life-insurance/genetic-testing/

[2] https://www.flsenate.gov/Session/Bill/2020/1189/Analyses/h1189c.COM.PDF

exception for genetic test results if the results are in the applicant's medical record and provide a diagnosis.

Colorado – SB21-169

SB 21-169, was enacted in 2021 Colorado Regular Session, and prohibits insurers of any type from use of consumer data to discriminate on the basis the individual's race, nationality, ethnicity, religion, sex, sexuality, disability, gender identity, or gender expression in any insurance practice[3]

The act requires insurers to demonstrate how they plan to use an external data in the Stakeholder Engagement Process. The five-step process requires insurers to, first: provide the Colorado Division of Insurance information concerning external data sources and formulas being applied for the type of insurance, second: to provide an explanation of the manner the insurer uses external data sources, third: to create a risk management framework that determines whether the insurer's external data sources discriminate or not, fourth: to formulate an assessment of risk management framework and actions to minimize risk, and lastly, to conduct an attestation of insurer's risk officer[4].

Maine – H.P.800 & Illinois – H.2189

Both as introduced, would have prohibited life insurers from using genetic information in underwriting. The bills were amended to strike underwriting restrictions.

H.P.800 had an accepted majority report on June 10, 2021. The intention behind this bill was to prohibit discrimination on the basis of genetic information or genetic testing.

H.2189 was passed May 21, 2019, modeled as an amendment to Genetic Information Privacy Act. As it was passed, language that has specified the prohibition of an insurer from disclosing protected information for underwriting purposes[5].

As they passed, these bills prohibited direct-to-consumer testing companies from releasing test results without consumer consent.

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[3] https://leg.colorado.gov/bills/sb21-169

[4] https://leg.colorado.gov/sites/default/files/2021a_169_signed.pdf

[5] https://www.ilga.gov/legislation/BillStatus.asp?DocNum=2189&GAID=15&DocTypeID=HB&SessionID=108&GA=101

Conclusion

To approach S.247, it is critical to remember how both sides mitigate risks - individual policyholders get genetic tests to mitigate risks to their health, and insurance companies work to mitigate risk to provide care for individuals. S.247 furthers consumer protection of genetic information against discrimination at the hands of insurance companies. Insurance companies must protect themselves and their solvency.