

Genetic Information and Life Insurance Underwriting: Entering a Critical Stage

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1. State legislation
2. Critical stage
3. How valuable is genetic testing in underwriting?
4. Other countries
5. Public policy favors genetic testing by at-risk individuals

1. State legislation

1990-2019 Life insurance industry
successfully avoided significant
limits on the use of genetic
information in underwriting.

No applicable federal legislation
(unlike health insurance in GINA/ACA)

Laws enacted at the state level have serious limitations:

- (1) Apply only to discrimination against unaffected carriers of recessive disorders (e.g., California, Maryland)
- (2) Do not prohibit genetic discrimination that is actuarially justified (e.g., Massachusetts, Montana)

In Florida in 2019, SB 258, a bill to prohibit genetic discrimination in life, disability, and long-term care insurance without actuarial justification was defeated after a positive committee vote.

Note: Unfair Trade Practice laws in every state already prohibit any adverse treatment without actuarial justification.

(3) Prohibit life insurers from requiring genetic testing of an applicant or using the results of a family member's genetic test, but do not prohibit use of genetic test results in an applicant's medical record (Vermont)

2. Critical stage

“Critical Stage”

- Over 25 million Americans have had direct-to-consumer genetic testing (e.g., 23andMe); this is “off record.”
- Most is ancestry, but several million are for health risk assessment, with at least 1-2 million more each year.
- The real or perceived effects of adverse selection have reached a tipping point.

New Technologies Raise Additional Underwriting Concerns

(1) Polygenic risk scores – Combines GWAS data, health history, and environmental measures (can be hundreds of data points); uses algorithms to get a polygenic risk score.

Already are being marketed to individuals.

(2) Epigenetic age estimators – Based on DNA methylation at numerous sites in the genome.

Already are used by a few life insurance companies (e.g., YouSurance)

3. How valuable is genetic testing in underwriting?

What Kind of Genetic Test Information Might Be Valuable in Underwriting?

1. Must be an adult-onset disorder.
2. Must have high penetrance.
3. Must have high absolute risk.
4. Must have high relative risk.
5. Must have high mortality rate.
6. Must be a lack of family history.
 - a. de novo mutation
 - b. young adult applicant before parental onset
 - c. orphan, adoptee, misattributed paternity

What Conditions Meet These Criteria?

1. Early-onset Alzheimer's disease
2. Some neurodegenerative diseases (ALS, HD)
3. Some hereditary cancers (breast, colon)
4. Some syndromic conditions (Li-Fraumeni, Lynch)

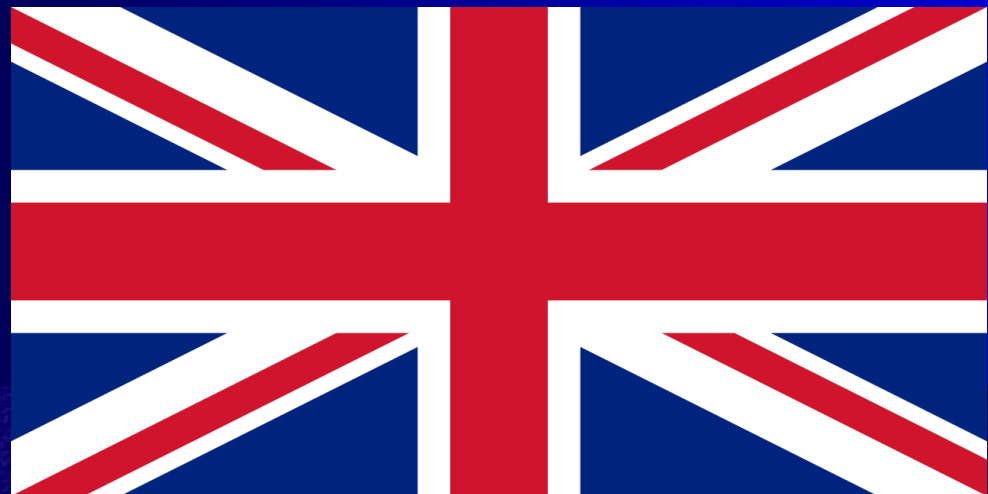
Important: Just because a condition meets these criteria does not mean that an individual with a positive test cannot be offered coverage (e.g., BRCA).

4. Other countries

U.S. Lags Much of the World

Almost all other high income countries prohibit the use of genetic information in life insurance underwriting.

United Kingdom (2001/October 2018) – Government and the Association of British Insurers agreed to a Voluntary Code of Practice.



Results of a predictive genetic test may be required only if approved by the Genetics and Insurance Committee (joint government/industry). So far, only Huntington's disease has been approved.

Results may only be used for insurance at or above the following thresholds:

Life insurance £ 500,000

Critical illness £ 300,000

Income protection £ 30,000/year

Canada (2015) – Canadian Life and Health Insurance Association (99% of industry) adopted a voluntary Industry Code on Genetic Testing; agree not to require predictive genetic test for life insurance coverage below C\$ 250,000 (~\$190,000).

Purpose was to forestall nondiscrimination legislation.



Canada (2017) – Federal Bill S-201, the Genetic Nondiscrimination Act, prohibits imposing genetic testing for any “good or service.” Violation is a criminal offense punishable by a fine up to C\$ 1 million and/or 1 year in prison. Challenge to the constitutionality of the law is currently pending in the Supreme Court of Canada.

Australia – (July 1, 2019) – Life insurance industry adopted a voluntary moratorium on the use of genetic test results for policies at or below Au\$ 500,000.



Other countries that regulate genetic information in life insurance underwriting: Argentina, Belgium, Bulgaria, Denmark, Estonia, France, Germany, Iceland, Ireland, Israel, Lithuania, Luxembourg, the Netherlands, Portugal, Sweden, and Switzerland.

5. Public policy favors not discouraging genetic testing by at-risk individuals

Genetic Testing Saves Lives

Early detection of certain gene-mediated illnesses, especially cancers, is essential.

Some examples:

- Hereditary nonpolyposis colon cancer (130,000/year)
- Hereditary diffuse gastric cancer (21,500/year)

Many people with a family history of genetic disease decline testing because they are concerned about possible “genetic discrimination.”

This includes clinical and research testing.

Our public policy must be to encourage these at-risk people to be tested.

Genetic Information Nondiscrimination Act (GINA) addresses health insurance (and employment)

Life insurance regulation is certainly next.

Life insurance	10 million policies
Disability insurance	500,000 policies
Long-term care insurance	100,000 policies

To summarize:

1. No state law prohibits life insurers from using the results of genetic tests contained in an applicant's health record.
2. Genetic test results have a much less significant underwriting value than widely believed.
3. Life insurers will be placed in an increasingly difficult position by real and assumed adverse selection attributable to direct-to-consumer genetic testing and new technologies (e.g., polygenic risk scores, epigenetic age estimators).
4. Genetic testing saves lives.

To be clear:

- I am not advocating for guaranteed issue, community rated policies.
- I am not opposing the use of other health information, environmental factors, or family history in medical underwriting.
- I am proposing that genetic test results (diagnostic and predictive) should not be used in underwriting life insurance.

Other Questions to Address

1. May at-risk individuals voluntarily submit favorable genetic test results?
2. May insurers use results of genetic tests above a certain amount?
3. Would industry-wide policies eliminate the need for legislation?
4. Would industry-wide policies violate antitrust laws?

References

Mark A. Rothstein, Time to End the Use of Genetic Test Results in Life Insurance Underwriting, *Journal of Law, Medicine & Ethics* vol. 46, 794-801 (2018).

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