Time to End the Use of Genetic Test Results in Life Insurance Underwriting

Currents in Contemporary Bioethics

Mark A. Rothstein

During the 1990s, as the researchers working on the Human Genome Project were racing to map and sequence the human genome, many members of the public were concerned that predictive genetic information could be used to discriminate in employment and various forms of insurance, including life, health, disability, and long-term care.[1] By the end of the decade, 48 states had enacted laws prohibiting genetic discrimination in health insurance[2] and 35 states prohibited genetic discrimination in employment.[3] In 2008, Congress enacted the Genetic Information Nondiscrimination Act (GINA),[4] which outlawed discrimination based on genetic information in health insurance and employment. There has been little meaningful legislation enacted at the state or federal level to limit the use of genetic information in other types of insurance, including life insurance. Most state laws on genetics and life insurance merely require insurers to obtain informed consent before performing genetic tests[5] or prohibit the use of genetic information in underwriting unless there is a sound actuarial justification.[6]

There are several reasons why neither Congress nor state legislatures have enacted significant laws prohibiting genetic discrimination in life insurance. Generally speaking, there has been inadequate public demand for such legislation and entrenched industry opposition. This article argues that sound public policy demands an end to the use of genetic test results in underwriting by life insurance companies. The article addresses the main rationales invoked for resisting any change from the status quo and presents the public policy considerations supporting an end to the use of genetic test results.

The article distinguishes genetic test results from predictive genetic information. Genetic test results refers to both diagnostic and predictive test results on a single gene test, multiplex gene panel, whole genome sequencing (WGS), whole exome sequencing (WES), or comparable genetic or genomic tests. Predictive genetic information refers to genetic information obtained from an individual's medical record or the health histories of family members supplied by the applicant. There have been no reports of any American life insurance companies requiring genetic testing as a condition of applying for life insurance coverage, but all life insurers may obtain and use genetic test results from the clinical records of applicants. Life insurers also may learn an applicant's genetic information or genetic risks from his or her health history in clinical records as well as from the family health history supplied by the applicant.

If life insurance companies refrained from or were prohibited by law from accessing and using the genetic test results of applicants, genetically at risk individuals are likely to be more willing to undergo genetic testing in clinical settings. Such a change would promote early medical intervention; for many individuals it would mean improved health and increased life expectancy. As discussed below, life insurance companies would still be able to assess and underwrite genetic risks based on current health status, family health history, and other customary sources of information. To be clear, this article is not proposing a blanket prohibition on life insurers using *any* predictive genetic information, including clinical information in the applicant's medical record and

Mark A. Rothstein, J.D., *is the Herbert F. Boehl Chair of Law and Medicine and Director of the Institute for Bioethics, Health Policy and Law at the University of Louisville School of Medicine.*

About This Column

Mark A. Rothstein serves as the section editor for *Currents in Contemporary Ethics*. Professor Rothstein is the Herbert F. Boehl Chair of Law and Medicine and the Director of the Institute for Bioethics, Health Policy and Law at the University of Louisville School of Medicine in Kentucky. (mark.rothstein@louisville.edu)

The Journal of Law, Medicine & Ethics, 46 (2018): 794-801. © 2018 The Author(s)
DOI: 10.1177/1073110518804243

the health history of family members. Such a fundamental change in underwriting would go too far with negative consequences for life insurance pricing and affordability.

The Increase in off-Record Genetic Test Information will Tempt some Life Insurers to Require their Own Genetic Testing

When no individuals had their genomes sequenced and relatively few had genetic testing, life insurers could safely adopt the strategy of not requiring applicants to undergo genetic testing, but insisting on access to any genetic test results in an applicant's medical record and requiring disclosure of family health information. This strategy will be less effective as genetic and genomic testing continues to become less expensive and therefore more widely available. In 2003, when researchers published the first reference sequence of the human genome, the cost of genome sequencing for one individual was about $2.7 billion.[7] In the clinical setting, medical geneticists tended to order tests of single genes, which cost only a few hundred dollars per test. Today, the cost of WGS has declined to below the "holy grail" of $1000[8] and the price is expected to drop to $100.[9] Genomic information is now widely used in clinical settings and is often the standard of care for oncology, rare disorders, and pharmacogenomics.[10]

Illumina, Inc., is the largest genome sequencing company in the United States. In 2014, Francis de Souza, its president, stated that by 2017 Illumina would increase its sequencing to about 1.6 million genomes a year by doubling sequencing output about every year.[11] Based on these projections, and adding the capacity of other companies and laboratories, it is likely that tens of millions of Americans already have had genome or exome sequencing. Researchers also are generating voluminous amounts of sequence data. For example, the NIH's All of Us Research Program is creating a biorepository containing WGS data from one million volunteers and returning the results.[12]

One of the greatest concerns of life insurers is the emergence of direct-to-consumer genetic and genomic testing and its projected growth. Companies such as 23andMe, Color Genomics, and Helix enable individuals to obtain exome sequencing on a confidential basis. In addition, inexpensive and increasingly accurate hand-held sequencing devices further raise the possibility of genome sequencing performed by individuals themselves.[13] Off-record genome sequencing and genetic testing can give rise to information asymmetry, whereby potential applicants for life insurance have more predictive health information than life insurers. In such an atmosphere, one or more of the 872 life insurance companies in the United States[14] might require applicants to undergo some form of genetic testing.[15] The likely public outcry could result in legislative restrictions on insurers or other actions that are difficult to predict.

Insurer Access to Genetic Test Results is Unnecessary to Avoid Adverse Selection

Although life insurance companies continually update their underwriting criteria and risk classification, the basic principles of actuarial science have not changed. Because it is impossible to predict the life expectancy of any particular individual, underwriters place individuals in groups with others with similar risks. The ability to accurately underwrite risks, however, is undermined by adverse selection or anti-selection, the tendency of individuals most in need of insurance to apply for insurance or to apply for greater amounts of insurance.[16] In my view, two types of adverse selection could be applicable. General adverse selection means that individuals are more likely to apply for life insurance or in greater amounts due to information about their need for insurance. Specific adverse selection means that individuals will apply for insurance with a particular company because of its known or assumed underwriting practices. Insurer policies on the use of genetic information could affect both types of adverse selection.

The use of predictive genetic information obtained or inferred from an applicant's health records or the health histories of family members is an established part of medical underwriting. The American life insurance industry's longstanding opposition to any limitation on its use of genetic test results in applicants' health records seems to reflect an assumption that genetic test results are especially predictive of mortality risk. In fact, genomic and genetic test results are less valuable to the calculation of mortality risk than might be assumed. One reason is that non-genetic information life insurers ordinarily obtain is sufficient for assigning individuals to the appropriate risk category. In particular, age, current health status, occupation, hobbies, smoking and other behavioral risk factors, and family health history are extremely valuable.[17] Also of significance is the amount of life insurance individuals are seeking relative to their income and health information obtained from previous insurance applications available through the Medical Information Bureau.[18] The other reason is that scientific predictions of mortality risk for asymptomatic individuals are complex and the significance of many newly identified genomic variants is unknown.

Relatively few genetic-related disorders have demonstrable importance for medical underwriting in life insurance because they must have the following six characteristics. First, they must be adult-onset. A person having a disorder with childhood onset, such as type 1 diabetes, will be symptomatic by the time of a typical application for life insurance. Second, they must have a high penetrance, which means a significant likelihood that a gene variant will be expressed. Third, they must have a high absolute risk, meaning there is a substantial risk that an individual with a risk-conferring genotype will get the disorder. Fourth, they must have a high relative risk, meaning that individuals with the risk-conferring genotype are significantly more likely to express the particular condition

The Journal of Law, Medicine & Ethics, 46 (2018): 794–801. © 2018 The Author(s)

than other individuals. Fifth, there must be a high mortality rate for the condition and a lack of effective treatment, especially if the disease is not detected early. Sixth, there must be a lack of family history of the disorder, because if there were a family history then genetic test results would be less valuable. The lack of family history for a life insurance applicant with a positive genetic test is most likely to occur when a young adult applies for life insurance before the applicant's parent, the carrier of an autosomal dominant allele, has begun to exhibit symptoms or the affected parent has died of other causes before reaching the age when the genetic-related condition would manifest.[19] Some conditions meeting these six criteria are early-onset Alzheimer's disease;[20] some neurodegenerative diseases, such as amyotrophic lateral sclerosis[21] and Huntington disease;[22] some hereditary cancers, such as some breast and colon cancers; and some syndromic conditions, including Li-Fraumeni syndrome[23] and Lynch syndrome.[24]

The mortality risk for women with a BRCA 1 or BRCA 2 breast cancer mutation illustrates the principle that the mere presence of a risk-conferring allele does not support denying life insurance coverage. It has been widely reported that a woman with a BRCA mutation and a strong family history of breast or ovarian cancer has an 85% lifetime risk of breast cancer and a 60% lifetime risk of ovarian cancer.[25] In women without an affected first-degree relative, the lifetime risk of breast cancer drops to 60.8% for BRCA 1 and 63.1% for BRCA 2.[26] On a population-wide basis, including women with no family history of breast cancer, only 46% of women with a BRCA 1 mutation will develop breast cancer by age 70[27] and only 25% of those who develop breast cancer will die from it.[28] By the time they are 60, women with a breast cancer mutation who die are more likely to die of another cause.[29] Of actuarial significance:

> The prevalence of BRCA mutation carriers in the general population is estimated at between 1/800 and 1/1000. BRCA1 and BRCA2 mutation frequencies in breast and ovarian cancer patients unselected for family history or age at onset are generally low (<1-7% for BRCA1 and 1-3% for BRCA2).[30]

The clinical significance of a genetic predisposition also should be considered. Women who have a known genetic risk of breast cancer also tend to be more vigilant in cancer screening and therefore if they get breast cancer it is more likely to be diagnosed and treated at an earlier stage, which results in a lower mortality rate.[31] Furthermore, the efficacy of treatment for comparable disease in women with and without a BRCA mutation is similar.[32] Prophylactic surgery and chemoprevention for genetically at-risk women substantially lowers the mortality risk.[33] The combination of these factors strongly suggests that a genetic predisposition to breast cancer based on a BRCA mutation should not lead to a denial of life insurance coverage.[34] More broadly, few genetic test results have efficacy in medical underwriting for life insurance.

It is difficult to predict the effects of eliminating the use of genetic test results by American life insurance companies. In other developed countries, however, policies of not using genetic test results in underwriting does not seem to have resulted in major disruptions to the life insurance industry.

The Lack of Genetic Test Results will not Jeopardize the Financial Viability of the Life Insurance Industry

It is difficult to predict the effects of eliminating the use of genetic test results by American life insurance companies. In other developed countries, however, policies of not using genetic test results in underwriting does not seem to have resulted in major disruptions to the life insurance industry. Beginning in 2001, the Association of British Insurers adopted a voluntary moratorium on the use of genetic test information.[35] A series of subsequent agreements with the British government extended the moratorium through at least 2019.[36] British life insurers do not require applicants to disclose the results of predictive genetic tests up to the following limits: life £500,000, critical illness £300,000, and income protection £30,000 per year.[37] For policies in excess of these limits, insurers can collect and use the results of a genetic test only if the Genetics and Insurance Committee (GAIC), a government agency, has approved the test. So far, the GAIC has approved genetic testing only for Huntington disease for life insurance applications.[38]

In Canada, the Canadian Health and Life Insurance Association announced in 2017 the adoption of a code of conduct on genetic testing to take effect on January 1, 2018. The code stipulates that applicants need no longer disclose genetic test results when applying for new coverage worth C$250,000 or less.[39] The move was widely reported to be an attempt to preempt federal legislation.[40] If so, it was unsuccessful because new legislation approved in 2017 (Law S-201) prohibits the use of genetic information in any contract for goods and services.[41] The statute also amends the Canadian Criminal Code to include penalties of up to C$1

The Journal of Law, Medicine & Ethics, 46 (2018): 794-801.

million for violations.[42] Interestingly, the law does not use the word "insurance" because according to the Canadian Constitution the provincial governments regulate private insurance, but the new federal law applies to all contracts for goods and services, including insurance. A legal challenge to the law was brought by the Quebec government questioning the constitutional validity of the law.[43]

International agreements have long opposed genetic discrimination in various contexts. Since 1997, the Council of Europe's Convention on Human Rights and Biomedicine ("Oviedo Convention") prohibits the use of predictive genetic testing for discriminatory purposes.[44] Further, a provision in the 2012 Charter of Fundamental Rights of the European Union provides that any discrimination based on, among other things, "genetic features" "shall be prohibited."[45] Numerous countries explicitly prohibit the use of genetic test results by life insurers, including Argentina, Belgium, Bulgaria, Denmark, Estonia, France, Germany, Iceland, Ireland, Israel, Lithuania, Luxembourg, the Netherlands, Portugal, Sweden, and Switzerland.[46] Other European countries prohibit genetic discrimination in insurance through general antidiscrimination laws.[47]

Actuarial Fairness does not Equate with Moral Fairness

In the 1990s, many members of the public feared that insurance companies would incorrectly use genetic information and erroneously estimate their risk, thereby excluding them from or charging higher rates for various types of insurance, including life insurance. This fear was understandable because of the newly emerging nature of the science and the lack of trained geneticists. Erroneous underwriting practices fail to satisfy the legal and ethical requirements of actuarial fairness. In addition, actuarial fairness "expresses the moral judgment that fair underwriting practices must reflect the division of people according to actuarially accurate determination of their risks."[48] Today, there is less concern about actuarial fairness in insurance underwriting involving common genetic conditions, even though many genomic variants are of unknown significance. Overall, actuarial fairness is a necessary but insufficient element of moral fairness.[49]

Moral fairness exists when the availability of insurance furthers important societal interests, such as justice, beneficence, autonomy, and population health. Although life insurance and health insurance are different products for different social needs, health insurance is a good example of the quest for moral fairness in insurance. Until the last two decades health insurance underwriting in the United States only needed to satisfy actuarial fairness, and most individual and some group health insurance policies were medically underwritten to account for preexisting conditions or unacceptably high risks of future illness. The Health Insurance Portability and Accountability Act of 1996[50] prohibited these practices in employer-sponsored group health plans. The Affordable Care Act of 2010[51] prohibited these practices in all individual and group health insurance. Public policy embraced wider health insurance coverage as a way of increasing access to health care. The declared public policy of GINA is to encourage genetically at-risk individuals to undergo genetic testing without fearing possible economic harm.[52] Applying this rationale more broadly, all policies and practices that discourage voluntary genetic testing are contrary to public policy.

Maintaining the Privacy of Genetic Test Results will Save Lives

The most powerful argument in favor of ending the use of genetic test results in life insurance underwriting is that doing so will save lives. A wealth of survey data indicate that many at-risk individuals are reluctant to undergo genetic testing or genome sequencing for two main reasons.[53] First, some individuals do not think they can handle the psychological strain associated with a result indicating a high risk of serious illness.[54] Second, other individuals decline testing in clinical and research settings because they fear the potential economic consequences of the results in terms of genetic discrimination in employment and various types of insurance.[55] Genetic counselors confirm these survey results with numerous personal accounts.[56] The economic fears are rational, even though there have been few reported incidents of genetic discrimination. GINA only prohibits discrimination based on genetic information in health insurance and employment. The few state laws to address life insurance add little protection. One of the most restrictive state laws, in Vermont, prohibits genetic testing as a condition of applying for any type of insurance as well as using the results of genetic tests of family members.[57] Life insurance companies may still exclude from coverage or charge higher rates to individuals at genetically increased risks based on the results of genetic tests performed in the clinical setting and documented in an applicant's health record. Therefore, it seems that even in Vermont many individuals would be reluctant to undergo genetic testing.

For some at-risk individuals the failure to undergo genetic testing and to embark on heightened surveillance and appropriate prophylactic or therapeutic intervention can be catastrophic. This is especially the case for certain gene-mediated cancers, including hereditary nonpolyposis colon cancer,[58] familial adenomatous polyposis colon cancer,[59] and hereditary diffuse gastric cancer.[60] Early detection and timely intervention can markedly improve these individuals' long-term survival.[61] Prevention and early treatment options for other forms of cancer already exist or are on the horizon[62] and public policy should not deter at-risk individuals from obtaining genetic testing to clarify their risk, determine their options, and, where appropriate, begin implementing a clinical strategy. Once life insurance is purchased, the incentives of the individual and life insurer are aligned because both benefit from increased longevity of the individual.[63] Consequently, life insurers might consider

The Journal of Law, Medicine & Ethics, 46 (2018): 794–801. © 2018 The Author(s)

adopting policies of encouraging individuals who voluntarily undergo genetic testing to engage in appropriate follow-up.[64]

Life insurance is the Most important Area for Implementing Genetic Nondiscrimination Policies

As noted earlier, there are five main areas of public concern about possible genetic discrimination: employment, health insurance, life insurance, disability insurance, and long-term care insurance. To date, federal and state legislation has focused on health insurance and employment. Of the remaining areas of public concern, the large number of life insurance policies relative to disability insurance and long-term care insurance makes life insurance the most appropriate insurance focus for revising underwriting practices. Accordingly, a change in underwriting policy for life insurance would have the greatest effect in assuring at-risk individuals that it is safe to undergo genetic testing without fear of adverse economic consequences.

Despite relatively few incidents of alleged genetic discrimination, employment discrimination was one of the first areas for state legislation, and 35 states have enacted laws prohibiting genetic discrimination in employment.[65] GINA also prohibits such discrimination,[66] but there have been very few cases brought alleging genetic discrimination in employment.[67] Similarly, genetic discrimination in health insurance has been widely recognized as important by the states, and 48 states prohibit genetic discrimination in health insurance,[68] as does GINA.[69] Of even greater significance, the Affordable Care Act,[70] by prohibiting all medical underwriting in individual and group health insurance goes beyond GINA, which only provides protection to asymptomatic individuals.

Genetic discrimination in long-term care insurance based on genetic predisposition to Alzheimer's disease,[71] is of great concern for reasons of public policy, but the market for long-term care insurance has been shrinking.[72] In 2015, long-term care insurers issued only about 104,000 policies, a fraction of the number issued in prior years.[73] Numerous long-term care insurance companies have left the market because various economic factors contributed to a lack of profitability. One likely effect of the decline in long-term care insurance is an increased demand for Medicaid payments for nursing home care. This illustrates the close relationship between private insurance and governmental expenditures.

Many large employers offer limited group disability insurance as part of their benefits packages. Self-employed individuals with high incomes, such as physicians and lawyers, often apply for individual disability insurance. There were 545,775 individual disability insurance policies issued in 2015.[74] The policies are relatively expensive because insurers face large potential payouts for claims by high earners with many years of lost income. Social Security Disability Insurance (SSDI) provides payments to eligible individuals with permanent and total disability based on a formula that considers the amount of earnings before the individual became disabled. For 2018, the maximum benefit is $33,456 a year.[75]

Unlike the substantial benefits for SSDI, the Social Security death benefit of $255[76] affords virtually no financial security to one's heirs. Thus, life insurance continues to play an important role in protecting the financial futures of individuals and families. In 2016, there were approximately 11 million life insurance policies sold in the United States,[77] a figure that is about 17 times the total for individual disability and long-term care insurance combined. Therefore, concern about possible denial of life insurance is likely to be a leading economic reason why at-risk individuals decline genetic testing, and life insurance is the most appropriate target of new genetic nondiscrimination strategies.

Conclusion

Actuarial rate calculations for life insurance do not derive solely from immutable and incontestable statistics; for better or worse they also reflect social considerations. For example, it was not until after World War II that the life insurance industry adopted race-merged actuarial tables.[78] In the 1970s, red-lining of minority neighborhoods was used to deny minority residents mortgages and insurance.[79] From our vantage point today, it is hard to fathom that such practices existed. In the future, because of the relatively low underwriting benefit and high social cost it is quite likely that the United States will join the list of countries not permitting the use of genetic test results in underwriting life insurance. The only questions are when this more thoughtful approach will

Particularly as genetic research at a population level becomes increasingly prevalent, it is essential to develop normative frameworks. Ethical and legal questions, such as how to handle the likelihood of developing a disease based on genetic susceptibility that is highly variable, reflecting complex gene-gene and gene-environment interactions, will require the participation of the general public and the individuals, groups, and organizations that represent them.

The Journal of Law, Medicine & Ethics, 46 (2018): 794-801. © 2018 The Author(s)

be adopted and whether it will be implemented voluntarily by the life insurance industry or be imposed by government.

There is a seeming paradox in the analysis and main recommendation in this article. The article notes that tens of millions of people will undergo genetic or genomic testing in the years ahead, many of whom will be tested "off record." This suggests that to avoid adverse selection insurers will be more likely to require their own genetic testing. Nevertheless, this politically and socially troubling response is not the only option. The asymmetry in genetic information should be considered in the larger context.

I believe this is an opportune time for life insurance companies to choose the prudent and enlightened approach of ending the acquisition and use of genetic test results obtained from the clinical records of applicants. There are two reasons for this recommendation. First, genetic test results have considerably less value in calculating the mortality risk for asymptomatic individuals than is often assumed, especially when insurers are able to obtain traditional health information. Second, removing the disincentive for at-risk individuals to undergo genetic testing in the clinical setting is likely to save a substantial number of lives.

Eliminating the use of genetic test results will not make commercial life insurance a guaranteed issue, community-rated product or social welfare program. Life insurers will still be able to use an applicant's current health information and family health history in underwriting. In the past, the life insurance industry opposed any restrictions on the use of genetic test results or genetic information, but today some forward-thinking life insurance companies are reconsidering the issue. All life insurers are likely to regard only ending the use of an applicant's genetic test results as less disruptive of underwriting than a more comprehensive ban on using any genetic information.[80] Life insurance companies should disavow any use of genetic test results and elected officials should determine, based on industry action, whether legislation mandating such a change is necessary. A possible interim step might be the adoption of a moratorium for a limited number of years on the use of genetic test results, which would allow the industry and policy makers the opportunity to study the effects of such a policy.

An important definitional question is whether the policy should apply to predictive genetic testing or whether it also should apply to diagnostic genetic testing.[81] There are two reasons why it should apply to both types of genetic testing. First, even a "diagnostic" test is predictive because it establishes or confirms the likely course of an individual's illness, including the economic and social implications for the individual and the individual's family. Second, public policy should not discourage either type of genetic testing so that individuals can get timely and appropriate medical intervention as well as providing information that may be significant for the health of family members.

There are many other policy questions that need to be addressed, including the following: (1) whether an insurer may require or use the results of genetic tests of family members; (2) whether genetically at-risk individuals may voluntarily submit favorable genetic test results; (3) whether insurers may use genetic test results for life insurance policies above a certain amount and, if so, what amount; (4) whether insurers may charge higher rates to individuals at a genetically increased risk and, if so, how much; (5) whether genetic test results may be used for certain approved genetic tests and, if so, how the approval process would work; (6) whether legislation would be necessary if there were an industry-wide policy of not using genetic test results; and (7) whether antitrust laws would prevent the adoption of such an industry-wide policy.

Resolving these remaining issues will take careful deliberation, but reasonable policies are feasible once the stakeholders are committed to eliminating the disincentive for at-risk individuals to undergo genetic testing. This article asserts that life insurers in the United States can change their underwriting practices without disrupting their large and important industry. It is time to end the use of genetic test results in life insurance.

Note

The author has no conflicts to disclose.

Acknowledgments

Support for writing this article was provided by NIH grant R01HG008605, LawSeq: Building a Sound Legal Foundation for Translating Genomics into Clinical Application (Clayton, Lawrenz, and Wolf, PIs).

Many thanks to the following individuals for reading an earlier draft and providing extremely helpful comments: Paul Billings, Kyle Brothers, Ellen Clayton, Mike DeKoning, Robert Green, Yann Joly, Esther Knapp, Bonnie LeRoy, Tom Morgan, and Anya Prince. Simon Isham, J.D. 2018, University of Louisville Brandeis School of Law, provided valuable research assistance. The author is solely responsible for all statements in the article.

References

1. P. Billings et al., "Genetic Discrimination as a Consequence of Genetic Testing," *American Journal of Human Genetics* 50, no. 3 (1992): 476-482; NIH-DOE Working Group on Ethical, Legal, and Social Implications of Human Genome Research, "Genetic Information and Health Insurance" (1993).
2. National Human Genome Research Institute (NHGRI), Genome Statute and Legislation Database, *available at* <https://www.genome.gov/policyethics/legdatabase/pubsearchresult.cfm> (last visited August 3, 2018).
3. *Id.*
4. 42 U.S.C. § 2000ff.
5. Colo. Rev. Stat. § 10-3-1104; Minn. Stat. § 72A.139; N.Y. Ins. Law § 2615; Or. Rev. Stat. § 746.135.
6. Kan. Stat. Ann. § 40-2259; Me. Rev. Stat. Ann. tit. 24A, § 2159-C; N.M. Stat. Ann. § 24-21-1 et seq.; Wis. Stat. Ann. § 942.07. These laws are of questionable necessity because unfair trade practice laws in every state prohibit the pricing of any insurance product that is not actuarially justified.
7. National Human Genome Research Institute, "Human Genome Project Completion: Frequently Asked Questions: How Much Did the Human Genome Project Cost U.S. Taxpayers?," *available at* <https://www.genome.gov/11006943/human-genome-project-completion-frequently=asked-questions> (last visited August 3, 2018).
8. E.C. Hayden, "Is the $1,000 Genome for Real?" *Nature* 507, no. 7492 (2014): 294-295.

The Journal of Law, Medicine & Ethics, 46 (2018): 794-801. © 2018 The Author(s)

9. Illumina, Press Release, *Illumina Introduces the NovaSeq Series – A New Architecture Designed to Usher in the $100 Genome*, *available at* <https://www.illumina.com/company/news-center/press-releases/press-release-details.html?newsid=2236383> (last visited August 3, 2018).
10. L. Dong et al., "Clinical Next Generation Sequencing for Precision Medicine in Cancer," *Current Genomics* 16, no. 4 (2015): 253-263.
11. A. Regalado, "EmTech: Illumina Says 228,000 Human Genomes Will Be Sequenced This Year," *MIT Technology Review*, Sept. 24, 2014, *available at* <https://www.technologyreview.com/s/531091/emtech-illumina-says-228000-human-genomes-will-be-sequenced-this-year> (last visited August 3, 2018).
12. National Institutes of Health, All of Us Research Program, *available at* <https://allofus.nih.gov> (last visited August 3, 2018).
13. M. Jain et al., "Nanopore Sequencing and Assembly of a Human Genome with Extra-Long Reads," *Nature Biotechnology* 36, no. 4 (2018): 338-345, doi:10.1038/nbt.4060.
14. Insurance Information Institute, Facts + Statistics: Industry Overview, *available at* <www.iii.org/fact-statistic/facts-statistics-industry-overview> (last visited August 3, 2018).
15. A related technology already is used in the secondary life insurance market. GWG Holdings purchases life insurance policies in the secondary market. Its subsidiary, Life Epigenetics, uses epigenetic technology (levels of certain methylated biomarkers) to predict life expectancy of the policyholders. See "Life Epigenetics, GWG Holdings' Insurtech Subsidiary, Releases Infographic Timeline of the Impact of Epigenetics on the Insurance Industry," December 7, 2017, *available at* <https://globenewswire.com/news-release/2017/12/07/1247777/0/en/Life-Epigenetics-GWG> (last visited August 3, 2018). Although there is little evidence in the literature confirming the validity of this test, the company plans to sell the technology to other insurance companies. "GWG Life Becomes First Insurtech Firm to Collect Epigenetic Samples to Analyze Biomarkers of Life Insurance Policy Holders," March 2, 2017, *available at* <https://globenewswire.com/news-release/2017/03/02/930557/0/en/GWG-Life-Becomes-First> (last visited August 3, 2018).
16. K. Subramanian et al., "Estimating Adverse Selection Costs from Genetic Testing for Breast Cancer and Ovarian Cancer: The Case of Life Insurance," *Journal of Risk and Insurance* 66, no. 4 (1999): 531-550.
17. Family health history would be even more important if new laws were enacted or insurance industry policies changed to prohibit the use of individual genetic test results. Therefore, disclosure of family health history will be more important. See A. Prince, "Tantamount to Fraud: Exploring Non-Disclosure of Genetic Information in Life Insurance Applications as a Grounds for Policy Rescission," *Health Matrix* 26, no. 1 (2016): 255-307.
18. Facts about MIB, *available at* <http:www.mib.com/facts_about_mib.html> (last visited August 3, 2018).
19. Other reasons for a lack of family history include a new mutation or low penetrance, the applicant is an orphan or adoptee, or there is misattributed parentage.
20. D. Campion et al., "Early-Onset Autosomal Dominant Alzheimer Disease: Prevalence, Genetic Heterogeneity, and Mutation Spectrum," *American Journal of Human Genetics* 65, no. 3 (1999): 664-670.
21. A. Fuglsang-Frederiksen, "Diagnostic Criteria for Amyotrophic Lateral Sclerosis (ALS)," *Clinical Neurophysiology* 119, no. 3 (2008): 495-496.
22. J. F. Gusella and M. MacDonald, "Genetic Criteria for Huntington's Disease Pathogenesis," *Brain Research Bulletin* 72, no. 2 (2007): 78-82.
23. M. Hiseda et al., "Multiple Primary Cancers in Families with Li-Fraumeni Syndrome," *Journal of the National Cancer Institute* 90, no. 8 (1998): 606-611.
24. H.T. Lynch, "Review of the Lynch Syndrome: History, Molecular Genetics, Screening, Differential Diagnosis, and Medicolegal Ramifications," *Clinical Genetics* 76, no. 1 (2009): 1-18.
25. D. Ford et al., "Risk of Cancer in BRCA 1-Mutation Carriers," *Lancet* 343, no. 8899 (1994): 789-792.
26. M.K. Metcalfe et al., "The Risk of Breast Cancer in *BRCA 1* and *BRCA 2* Mutation Carriers without a First-Degree Relative with Breast Cancer," *Clinical Genetics* 93, no. 5 (2017): 1063-1068, doi: 10.1111/cge.1391.
27. S. Chen et al., "Characterization of BRCA1 and BRCA2 Mutations in a Large US Sample," *Journal of Clinical Oncology* 24, no. 6 (2006): 863-871.
28. J.A. Lowden, "Underwriting Genetic Diseases," in R.D.C. Brackenridge, R.S. Croxson, and R. Mackenzie eds., *Medical Selection of Life Risks*, (Swiss Re 5th ed.) (London: Palgrave Macmillan 2006): 99-114.
29. *Id.*
30. J. Balmana, O. Diez, and M. Castiglione, "BRCA in Breast Cancer: ESMO Clinical Recommendations," *Annals of Oncology* 20, no. Supp. 4 (2006): iv19-iv20, *available at* <https:// doi.org/10/1093/annonc/mdp116> (last visited August 3, 2018).
31. J.A. Lowden, "Genetic Risks and Mortality Rates," in M.A. Rothstein, ed., *Genetics and Life Insurance: Medical Underwriting and Social Policy* (Cambridge, MA: MIT Press, 2004): 95-118, 108.
32. E.R. Copson et al., "Germline BRCA Mutation and Outcome in Young-Onset Breast Cancer (POSH): A Prospective Cohort Study," *Lancet Oncology* 19, no. 2 (2018): 169-180, *available at* <http:dx.doi.org/10.1016/s1470-2045(17)30891-4> (last visited August 3, 2018).
33. X. Li et al., "Effectiveness of Prophylactic Surgeries in *BRCA1* or *BRCA2* Mutation Carriers: A Meta-Analysis and Systematic Review," *Clinical Cancer Research* 22, no. 15 (2016): Of1-OF11, doi:10.1158/1078-0432.CCR-15-1465.
34. J.A. Lowden, *supra* note 31.
35. Association of British Insurers, "Concordat and Moratorium on Genetics and Insurance," HM Government, *available at* <https:www.abi.org.uk/globalassets/sitecore/files/documents/publications/public/2014/genetics/concordat-and-moratorium-on-genetics-and-insurance.pdf> (last visited August 3, 2018).
36. *Id.*
37. *Id.*
38. *Id.*
39. "Canadian Life Insurers to Limit Use of Genetic Test Results," *The Canadian Press*, January 11, 2017, *available at* <http://www.cbc.ca/news/business/canada-life-insurance-genetic -testing-1.3930664> (last visited August 3, 2018).
40. *Id.*
41. Genetic Non-Discrimination Act, R.S.C. 2017, c.3.
42. Genetic Non-Discrimination Act, R.S.C. R.S.C. 2017, c.3, s.7 par. (a).
43. H. Roy, "Genetic Non-Discrimination Act: Quebec Questions Law's Constitutionality," *Insurance and Investment Journal* (2017), *available at* <https://insurance-journal.ca/article/genetic-non-discrimination-act-quebec-questions-laws-constitutionality> (last visited August 3, 2018).
44. Council of Europe, Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (Oviedo), articles 11 and 12, https://www.coe.int>conventions (last accessed August 3, 2018).
45. Charter of Fundamental Rights of the European Union art 21, 2012 O.J.C. 326/391.
46. Y. Joly et al., "Normative Approaches to Address Genetic Discrimination: Placebo or Panacea?" (2017), *available at* <http://ssrn.com/abstract=2911199> (last accessed August 3, 2018).
47. *Id.*
48. N. Daniels, "The Functions of Insurance and the Fairness of Genetic Underwriting," in M.A. Rothstein, ed. , *Genetics and Life Insurance: Medical Underwriting and Social Policy* (Cambridge, MA: MIT Press, 2004): 119-145, 124.
49. For an argument in support of "rational discrimination" as compared to the

The Journal of Law, Medicine & Ethics, 46 (2018): 794-801. © 2018 The Author(s)

current U.S. status quo, see A. Prince, "Insurance Risk Classification in an Era of Genomics: Is a Rational Discrimination Policy Rational?" *Nebraska Law Review* 94, no. 3 (2018): 624-687.
50. 42 U.S.C. § 300gg-300gg-2.
51. Patient Protection and Affordable Care Act of 2010, 42 U.S.C. § 18001 et seq. (2010).
52. For example, section 2(5) of GINA provides that the purpose of the law is to "fully protect the public from discrimination and to allay their concerns about the potential for discrimination, thereby allowing individuals to take advantage of genetic testing, technologies, research, and new therapies."
53. M.A. Rothstein, "Policy Recommendations," *Genetics and Life Insurance: Medical Underwriting and Social Policy*, M.A. Rothstein, ed. (Cambridge, MA: MIT Press, 2004): 233-265, 234.
54. K. Aktan-Collan, "Predictive Genetic Testing for Hereditary Non-Polyposis Colorectal Cancer: Uptake and Long-Term Satisfaction," *International Journal of Cancer* 89, no. 1 (2000): 44-50; L. Lodder et al., "Attitudes and Distress Levels in Women at Risk to Carry a BRCA1/BRCA2 Gene Mutation Who Decline Genetic Testing," *American Journal of Medical Genetics* 119A, no. 3 (2003): 266-272.
55. R.C. Green, D. Lautenbach, and A.L. McGuire, "GINA, Genetic Discrimination, and Genomic Medicine," *New England Journal of Medicine* 372, no. 5 (2015): 397-399; E. Penziner, "Perceptions of Discrimination among Persons Who Have Undergone Predictive Testing for Huntington Disease," *American Journal of Medical Genetics* 147B, no. 3 (2008): 320-325; and J.O. Robinson, "Participants and Study Decliners' Perspectives about the Risks of Participating in a Clinical Trial of Whole Genome Sequencing," *Journal of Empirical Research on Human Research Ethics* 1-10 (2016), doi: 10.1177/1556264615624078.
56. W.R. Uhlmann and S.F. Terry, "Perspectives of Consumers and Genetics Professionals," in M.A. Rothstein, ed., *Genetics and Life Insurance: Medical Underwriting and Social Policy* (Cambridge, MA: MIT Press, 2004): 147-172; M.A. Hall et al., "Genetic Privacy Laws and Patients' Fear of Discrimination by Health Insurers: The View from Genetic Counselors," *Journal of Law, Medicine & Ethics* 28, no. 3 (2007): 245-257.
57. Vt. Stat. Ann. tit. 18, § 9334(a).
58. For example, according to one calculation, if patients with a known risk of HNPCC had a screening colonoscopy it would increase their life expectancy by seven to nine years. H.F.A. Vasen et al., "A Cost Effectiveness Analysis of Colorectal Screening for Hereditary Nonpolyposis Colorectal Carcinoma Gene Carriers," *Cancer* 82, no. 9 (1998): 1632-1637.
59. C. Tomooda et al., "Cribriform-Morular Variant of Papillary Thyroid Carcinoma: Clue to Early Detection of Familial Adenomatous Polyposis-Associated Colon Cancer," *World Journal of Surgery* 28, no. 9 (2004): 886-889.
60. S. Sugimoto et al., "Recognition of and Recent Issues in Hereditary Diffuse Gastric Cancer," *Journal of Gastric Cancer* 50, no. 8 (2015): 831-843.
61. S.K. Plevritis et al., "Association of Screening and Treatment with Breast Cancer Mortality by Molecular Subtype in US Women, 2000-2012," *Journal of the American Medical Association* 319, no. 2 (2018): 154-164.
62. J. Kaiser, "'Liquid Biopsy' for Cancer Promises Early Detection," *Science* 359, no. 6373 (2018): 259.
63. I thank Robert Green for this observation.
64. I thank Paul Billings for this observation.
65. NHGRI, *supra* note 2. Much of the concern about employment discrimination is related to employers' role in providing health insurance benefits.
66. 42 U.S.C. § 2000ff.
67. M.A. Rothstein, J. Roberts, and T.L. Guidotti, "Limiting Occupational Medical Evaluations under the Americans with Disabilities Act and the Genetic Information Nondiscrimination Act," *American Journal of Law & Medicine* 41, no. 4 (2015): 523-567, 552-554.
68. NHGRI, *supra* note 2.
69. GINA, *supra* note 4.
70. ACA, *supra* note 51.
71. M.A. Rothstein, "Predictive Genetic Testing for Alzheimer's Disease in Long-Term Care Insurance," *Georgia Law Review* 35, no. 2 (2001): 707-733; D.H. Taylor, Jr., et al., "Genetic Testing for Alzheimer's and Long-Term Care Insurance," *Health Affairs* 29, no. 1 (2010): 102-108; C. Zick et al., "Genetic Testing for Alzheimer's Disease and its Impact on Insurance Purchasing Behavior," *Health Affairs* 24, no. 2 (2005): 483-490.
72. H. Gleckman, "The Traditional Long-Term Care Insurance Market Crumbles," *Forbes* (2017), *available at* <https:www.forbes.com/sites/howardgleckman/2017/09/08/the-traditional-long-term-care-insurance-market-crumbles#5116467a3ec3> (last August 3, 2018).
73. Federal Insurance Office, U.S. Department of the Treasury, "Report on Protection of Insurance Consumers and Access to Insurance" (2016), *available at* <https://www.treasury.gov/initiatives/fio/reports-and-notices/Documents/2016_FIO_Consumer_Report.pdf> (Last visited August 3, 2018).
74. Insurance Information Institute, Individual Disability Insurance, New Issues Sale, 2015, *available at* <https://www.iii.org/table-archive/20874> (last visited August 3, 2018).
75. Social Security Administration, "2018 Social Security Changes," *available at* <https://www.ssa.gov/news/press/factsheets/colafacts2018.pdf> (last visited August 3, 2018).
76. Social Security Administration, "Survivors Benefits," (2017), *available at* <https://www.ssa.gov/pubs/EN-05-10084.pdf> (last visited August 3, 2018).
77. American Council of Life Insurers, 2017 Fact Book, at 66, Table 7.1, *available at* <https://www.acli.com/Industry-Facts/Life-Insurers-Fact-Book> (last visited August 3, 2018).
78. M.L. Heen, "Ending Jim Crow Life Insurance Rates," *Northwestern Journal of Law & Social Policy* 4, no. 2 (2009): 360-399.
79. Daniels, *supra* note 48, at 129.
80. R.B. Meyer, "The Insurer Perspective," in M.A. Rothstein, ed., *Genetics and Life Insurance: Medical Underwriting and Social Policy* (Cambridge, MA: MIT Press, 2004): 27-47, 35.
81. I thank Jane Tiller for raising this issue.

The Journal of Law, Medicine & Ethics, 46 (2018): 794-801. © 2018 The Author(s)