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

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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 insurance² 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 tests⁵ 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

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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 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 \$1000⁸ 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 States¹⁴ 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 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 sclerosis²¹ and Huntington disease;²² some hereditary cancers, such as some breast and colon cancers; and some syndromic conditions, including Li-Fraumeni syndrome²³ 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 70²⁷ 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.

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 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 1996⁵⁰ prohibited these practices in employer-sponsored group health plans. The Affordable Care Act of 2010⁵¹ 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 horizon⁶² 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 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 \$255⁷⁶ 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 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.

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