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ISSUE BRIEF
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Genetic Information and Voluntary Life Insurance

Recent scientific advances, particularly those achieved by the Human Genome Project, have increased understanding of genetic processes and hold out hope for significant progress in the treatment of disease. At the same time, these advances have created concern that newly available information about the genetic makeup of individuals could be used to their disadvantage. Among the concerns most frequently raised is the question of the permissible use of genetic information in classifying risk for insurance coverage.

The process of risk classification is fundamental to voluntary life insurance. Risk classification places applicants into groups with roughly equivalent levels of risk,thereby ensuring their premium cost is commensurate with their risk level. Individuals who know, or suspect, that they have genetic disorders fear that this information could be used to deny or terminate insurance coverage. As a result, some individuals may avoid taking genetic tests that might provide potentially beneficial information about their condition and eventually help prevention or treatment. While these concerns are felt most strongly with regard to health insurance, in some cases they are extended to life insurance as well. This issue brief will examine fears regarding life insurance and risk classification, as well as offer possible solutions.

Genes and Insurability

The discovery of DNA has produced an explosion of research into the genetic structures that are fundamental to life in general and heredity in particular. Since 1990, the Human Genome Project, a $3-billion,fifteen-year joint effort of the National Institutes of Health and the U.S. Department of Energy, has worked toward the mapping of the human genome and sequencing of all genes. A complete map of the human genome could allow geneticists, researchers, and the medical profession to better understand and deal with disease. Early on in the project, it was recognized that as we map the human genome and gain the ability to test individuals for gene abnormalities, a host of ethical, legal, and social issues must be confronted. In recognition of the importance of such issues, the Ethical, Legal, and Social Issues (ELSI) program has been established as part of the Human Genome Project to actively consider the social implications of genetic testing.

The American Academy of Actuaries is the public policy organization for the United States actuarial profession, providing unbiased actuarial information to elected officials, regulators, and the news media. The Academy Task Force on Genetic Testing educates legislators and regulators about actuarial aspects of genetic testing and its use by insurers.

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The possibility of testing for abnormal genes has,in particular, raised fears about insurance and insurability. Insured individuals who learn that they carry genes linked to medical conditions worry that their coverage may be canceled or their premium raised. Potential applicants for insurance fear that they may be forced to take genetic tests, receive unwanted information about their health status, and perhaps be denied access to coverage now and in the future. Individuals also are concerned about the privacy of genetic information and the implications such information may have for their families. Researchers worry that fears about use of genetic information will deter volunteers for research projects. And finally, there is concern that insurers will use genetic tests to select only low-risk individuals, leaving many other individuals excluded from coverage. These concerns lead some to believe that insurers should not be permitted to take into account genetic test results in determining the cost and availability of insurance products.

Actuaries recognize that many individuals rely on the financial protection of life insurance and that the potential loss of insurability is a matter of great concern. On the other hand, actuaries also recognize that antiselection, the purchase of insurance more frequently and in higher amounts by individuals who are aware of risk that remains unknown to the insurer, could cause great financial damage to insurers and consequently to policyholders.

Separating Perception from Reality

Actuaries are trained to distinguish appearances from fact. In that spirit, the Academy Task Force on Genetic Testing has examined several commonly voiced concerns about the use of genetic information, with the aim of separating well-founded fears from misplaced anxieties. The following "perceptions" and corresponding "realities" reflect the current status of regulation and company practice but are not intended as the final word on the rapidly evolving role of genetic information in the life insurance industry.

1. *Perception: An individual who tests positive for a gene linked to a specific disease will contract that disease.*
   Reality: With few exceptions, a positive genetic test result indicates only an increased probability of developing such a disease.

A few genetic abnormalities will lead directly and certainly to disease. However, the vast majority of genetic conditions require a combination of genetic and environmental factors to result in disease. Almost all of us are born with genetic risk factors, but it is not possible to determine when, or even if, individuals who are predisposed to disease will actually contract it. The risk profile of many people who are predisposed to genetic diseases will continue to allow them to qualify as standard risks for life insurance, just as they do today.

2. *Perception: Life insurance companies will cancel coverage or raise premiums if harmful medical conditions are revealed by genetic tests.*
   Reality: Voluntary individual life insurance cannot be canceled, and premium increases are either prohibited or tightly restricted.

Fears of cancellation and premium increases are unfounded in the context of voluntary life insurance. Once a contract is established, it remains in force as long as premiums continue to be paid. Premium costs are set at the time the policy is issued and in most cases are fixed for the life of the policy. If not fixed, premiums may be changed only on a class basis and not for specific individuals. Guaranteed maximum premiums provide a further limitation on the insurer's ability to increase premiums.

3. *Perception: Genetic testing will cause more people to be denied life insurance.*
   Reality: Genetic tests will not have a uniform effect on availability of insurance. Some people could gain greater access to coverage; others with specific genetic conditions could see reduced access to coverage or higher premium costs.

The Academy Task Force on Genetic Testing anticipates that, like past medical advances, genetic testing will not in the aggregate reduce the ability to obtain insurance. As individuals are tested and learn how to manage genetic disorders, genetic testing should actually improve overall mortality. Thus, in the future an even greater percentage of applicants might be accepted for coverage.

However, the use of genetic tests will not have a uniform effect. Some people will benefit from greater access to coverage, while others with specific conditions may have reduced opportunity to obtain life insurance.

For example, an individual who suffers from hemochromatosis, or iron-rich blood, faces serious medical consequences if the condition is left undetected and untreated. However, if a test reveals genetic predisposition for the condition, early treatment can prevent complications and avoid early death due to the condition. With early detection and treatment,the individual will likely be classified a standard risk.

Persons with a family predisposition for Huntington's disease may also benefit from tests. Currently, an insurer cannot rule out the strong possibility that a person with a family history of Huntington's will develop the disease. However, if genetic tests reveal that the individual does not carry the Huntington's gene, standard life insurance coverage can be obtained.

A positive test for BRCA1 may reveal a predisposition to breast cancer that was not evident from other underwriting information. Depending on age and other factors, it is possible that the person may be deemed a higher risk than would have been presumed otherwise. Conversely, a negative test may improve the assessment of a person with a strong family history of breast cancer.

4. *Perception: Insurance companies may require applicants to take genetic tests.*
   Reality: While the Academy does not know of any life insurer that currently requires DNA-based tests, it is possible that such tests may be required in the future.

A 1994 Ohio Department of Insurance Task Force survey did not find a single health insurer that required genetic testing, and the American Academy of Actuaries is not aware of any life company that has such a requirement. At present, these tests are quite expensive and reveal a limited incidence of significant genetic abnormalities. As a result, the overall value of the information from insurer-required tests is currently far outweighed by the cost. In the future, it is possible that genetic tests will be more accurate, widely available, and inexpensive. History shows that when new techniques have beccome widely recognized and used in the medical community, insurers often choose to incorporate them into the underwriting process.

5. *Perception: Life insurers will require applicants to reveal results of genetic tests already performed.*
   Reality: To prevent antiselection, insurers may indeed require applicants to reveal such results.

The goal of individual life insurance underwriting is to classify applicants into groups with similar probabilities of death and to set premiums appropriately. If both insurer and applicant have the same amount of information, the applicant can be classified without antiselection. However, if an applicant has material information about a health condition that is unknown to the insurer, it is likely that the individual will bring a higher than normal risk to the insurer by applying more often and for larger amounts of coverage than they would have purchased. Ultimately, higher risks lead to increased costs. As premiums become insufficient to cover costs, the monetary impact will be felt by insurers, policyholders, and other potential applicants. Such antiselection is an activity that threatens the financial health of the individual voluntary insurance system. (For more information, see the Academy's issue brief, "Risk Classification and Voluntary Life Insurance.")

6. *Perception: It is difficult to recruit participants for genetic research studies because of insurance fears.*
   Reality: Some people may decline to participate in research projects because they fear loss of insurability.

Researchers currently report some difficulty in recruiting research study participants. This is a result of the informed consent process and fears about the use of information and resulting discrimination. As already noted, there is no reason to fear losing life insurance that is already in force or being singled out for a rate increase. Although there could be implications for new applicants,participation in a blind study that does not inform participants about their test results would have no effect on insurability.

7. *Perception: Insurers will not keep genetic test results confidential.*
   Reality: States require insurers to keep all underwriting information confidential.

Currently, an applicant's consent is required before an insurer is permitted access to personal medical records. Disclosure of this information is governed by regulation and law, and its use by insurers is tightly restricted. In the 1980s and early '90s, many states reviewed and strengthened their confidentiality laws in response to the AIDS epidemic, and the continuing regulatory trend is to toughen such safeguards.

8. *Perception: Genetic testing will alter the way life insurance is sold, resulting in decreased coverage.*
   Reality: The Academy Task Force on Genetic Testing believes that genetic testing will not greatly change the current life insurance market.

Insurers, like other businesses, are highly motivated to increase the number of new customers. In fact, they could not stay in business without them. Almost 1,700 companies and 200,000 agents market individual life insurance and have strong incentive to offer coverage to as many people as possible. In addition, some companies specialize in placing coverage that other companies deny.

Under existing underwriting criteria, 91 percent of applicants are offered coverage at standard or preferred rates, 5 percent are required to pay an extra premium, and 4 percent are denied coverage. These percentages have remained relatively constant over the last 40 years, even as diagnostic procedures have advanced and been incorporated into the underwriting process. Many genetically related conditions are currently identified through family histories, blood tests, examinations, and medical records. The manifestation of genetic abnormalities has always been implicitly taken into account by insurers.

Legislative Initiatives

In response to growing public concern, legislators at both the state and federal level have developed proposals to regulate the use of genetic information. Many of these initiatives are limited in scope to medical expense insurance, or reinforce well-established industry practices concerning confidentiality and disclosure of sensitive information. However, some legislative initiatives would go so far as to ban use of any genetic information. Such limitations are in conflict with the principles that underlie the financial soundness of voluntary life insurance.

It has been suggested that banning the use of information gained from genetic testing in risk classification would alleviate problems in recruiting research subjects, encourage individuals to seek out test results, and reduce insurance fears. Unfortunately, such proposals often contain two elements that are of serious concern to actuaries: the definition of "genetic test" and limitations on insurer knowledge of applicants' health status that would result in "asymmetric information."

Definition of genetic tests. It is commonly assumed that the term "genetic testing" is reasonably well-defined. Actually, the range of procedures that are sometimes considered genetic tests is broader than is commonly assumed.

DNA-based tests that tie specific conditions to specific genes are becoming more common as research advances through the work of the Human Genome Project. These tests are commonly cited in the debate about genetic privacy in underwriting. However, genetic information also is revealed through tests that insurers have used for many years. For example, blood and urine tests reveal evidence of genetic conditions, which insurers take into account in their risk classification procedures as a matter of course. Should such analyses be considered tests for genetic information similar to DNA-based tests? Any attempt to regulate use of genetic tests and the information derived from them should provide a clear definition of the tests being regulated.

The scope of such a definition would have a serious impact on insurers and consumers in the event of regulatory restrictions. A total ban or moratorium on information obtained from genetic tests,if broadly defined to include family and medical history, would severely hamper life insurance underwriting. Under such a ban, the mortality risk of some people would be unknown and hence the pool of insurance purchasers would soon include a disproportionate number of individuals at risk for premature death. Such individuals also would be more likely to purchase relatively large amounts of insurance. This antiselection would cause premium rates to rise, and a price spiral could ensue that would make life insurance unaffordable for most people. (For more information, see “Risk Classification and Voluntary Life Insurance.”)

Asymmetric information. Would a ban on the use of genetic information in life insurance underwriting merely prohibit insurers from asking for tests to be performed or would they also be barred from obtaining test results already known to the applicant? Clearly, a more encompassing ban would more completely remove applicant fears of genetic-based denial. However, from an actuary’s point of view there is a world of difference between the two prohibitions. Whenever critical information is known by the applicant and not the insurer, the asymmetry of information leads to antiselection and results in less affordable and available insurance. As prices rise, consumer buying patterns change, claim costs increase, and prices rise yet again to keep the system in balance. This rate spiral would not only affect affordability, but over the long term could also cause insurers to withdraw from the market or restrict coverage.

The impact of a ban on insurance company use of genetic tests would depend on the ban’s duration and the scope of the definition used. A moratorium on some types of tests would cause minimal disruption at first, but would have more severe consequences over time. This is primarily due to the fact that the new genetic tests of DNA currently are very expensive and provide little additional information about the probable mortality of an individual. When tests become more accurate,less expensive,and better able to detect a wide range of conditions, this will likely change.

Some argue that individuals would be more likely to use such helpful genetic information if life insurers were prohibited from using genetic information already known to applicants. Certainly, putting “off limits” information about minor conditions that have no severe implications for mortality would not have a serious impact on the insurer. However, in the case of a medical condition with more serious consequences, an information disequilibrium allows the applicant to choose the timing and amount of the insurance purchase. This is particularly significant for coverages such as life insurance, where the consumer chooses the benefit amount. A few people with serious conditions who purchase large amounts of coverage could skew an insurer’s portfolio of risk, exposing the insurer to unanticipated losses. This antiselection would have a great impact on rates, ultimately raising the cost of insurance to everyone.

Current Options, Possible Solutions

Although over 90 percent of life insurance applicants receive standard or preferred coverage, some individuals are declined. However, other options are available to individuals who are denied standard coverage:

- Coverage with an extra premium reflecting the added risk.
- Guaranteed issue insurance, which typically requires a higher premium and limits coverage in early policy years.
- Limited underwriting coverage, for which typically only a past personal history of serious disease causes denial of coverage. This is also a higher-premium coverage.
- Automatic group-insurance coverage through employers, trade associations, and affinity groups.
- Social Security survivors benefits.
- Purchasing insurance when young, before the onset of any serious disease or prior to taking a genetic test.
- Buying life-insurance options, before health problems become evident, that guarantee the right to purchase defined amounts of insurance at specific ages or life events.

These alternatives, combined with the wide availability of standard and preferred rate coverage, permit the vast majority of individuals who desire life insurance coverage to obtain it. However, the Academy realizes that the small percentage of individuals who are unable to obtain coverage may be seriously disadvantaged. On the other hand, a long-term ban on genetic testing would likely be disruptive to the voluntary life insurance system, ultimately hurting the American people by making life insurance more expensive and more difficult to obtain. For these reasons, the Academy believes that further research should be undertaken on the insurance-related problems raised by genetic testing. Such research should be directed toward identifying and building support for solutions that will both provide increased options for individuals with genetic disadvantages and maintain a sound life insurance system.

Finding Solutions

Physicians, insurers, and test recipients all are concerned with, and need information about, the implications of genetic test results on mortality and morbidity. Researchers typically focus on survival rates of five years or less. Actuaries, rigorously trained in mortality analysis, focus on lifetime mortality. A research project reviewing high-interest genetic abnormalities, such as BRCA1, BRCA2, or multiple sclerosis, would benefit from the combined efforts of researchers and actuaries. Not only would patients better understand their prognosis, but physicians could improve treatment modalities, and insurers could classify risk more accurately.

Options for Research Participants

Recognizing the difficulty of recruiting research subjects because of genetic-related fears,the following are offered for consideration:

- Encourage participants to purchase insurance before they participate in research studies.
- Explore the possibility of providing group insurance to research subjects.
- Require all participants to obtain “guaranteed insurability” coverage.

A Floor of Protection

Currently, Social Security provides a very limited amount of basic life insurance protection. As a result, many of the administrative mechanisms are already in place if there is a societal mandate to increase the amount and scope of the Social Security life insurance benefits. Other options for wider insurability involving government and insurance industry cooperation would need additional research into feasibility. Such solutions may include high-risk pools and other risk-sharing mechanisms.

Designing New Coverages

Some innovative coverages that could accommodate high-risk individuals are:

- Endowment coverage for individuals with little extra mortality in early durations and rapidly rising mortality in later ones.
- Limited early benefits for those with high short-term mortality risk, but with increased benefits for those who survive.
- Exclusions for certain disorders.
- Premium credits for proactive risk management.

Conclusion

These research proposals and new products could be helpful in answering questions and eliminating fears raised by genetic testing. The American Academy of Actuaries, working with the Actuarial Foundation and other sources, will explore these research options and product innovations. Those interested in learning more about the actuarial profession’s work on genetic testing, including comments on specific legislative proposals, are invited to contact the Academy for more information.