

The Potential Impact of Genetic Testing on Private Insurance

Robert Pokorski, MD, FACP

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INTRODUCTION

Good afternoon. I am Dr. Robert Pokorski, a medical director of Lincoln National Life Insurance Company. I would like to thank the Gannett Foundation and The Foundation for American Communications for co-sponsoring this meeting and providing me with an opportunity to visit with you today.

My primary focus on a day-to-day basis concerns the medical aspects of life insurance. This will be reflected in the prepared remarks that follow. I have, however, been accompanied by representatives from the American Council of Life Insurance and the Health Insurance Association of America who will be able to provide additional information in answer to questions that extend beyond my field of expertise.

Before addressing some of the specific concerns that will arise as a result of genetic testing, I would like to make a few general comments regarding insurers' perceptions of genetic tests at the present time.

From an underwriting point of view, insurers wish that genetic tests had not been developed. The current risk selection practices used by insurance companies have generally been accepted by the medical community and insurance-buying public, and these practices have permitted millions of people to purchase private insurance protection at an affordable price.

But diagnostic and therapeutic advances in the practice of medicine are both inevitable and desirable. Genetic testing represents such an advance. It will be thrust on a society that has had little experience in dealing with many of the complex ethical, medical, and social issues that will arise. Many facets of society -- including the private insurance industry -- will need to study the potential impact of this new technology and adapt.

Insurers have no current interest in nor enthusiasm for using genetic tests. Why? In the near future, these tests will probably deal with fairly uncommon impairments and/or the use of genetic tests will be reserved for selected situations in which the individual is thought to be at significant risk for developing a genetic disorder.

But at some point in the future, genetic testing

may become standard practice within the medical community. Having a panel of genetic tests performed may be as routine as having a cholesterol or blood sugar done. If and when this occurs, insurers will be forced to consider ordering genetic tests themselves. Such an action might be taken to enhance the risk selection process but even more likely it would be a defense against insurance applicants' use of significant knowledge about their potential health and longevity.

PRINCIPLES OF INSURANCE AND RISK CLASSIFICATION

A great deal of the present concern regarding future use of genetic tests by insurers stems from a lack of knowledge of the basic tenets of private, voluntary insurance. For this reason, I would like to briefly overview some of the fundamental principles of insurance before directly addressing issues associated with genetic testing.

Insurance is intended to provide financial protection against unexpected or untimely events. In particular, life and health insurance are purchased not in anticipation of imminent death or illness -- although it's understood that death is inevitable and serious illness is fairly common. Rather, life insurance is obtained to protect dependents or business associates from the financial disadvantages that can occur in the event of unexpected death and health insurance is meant to provide protection in the event of a significant financial loss associated with an unanticipated illness.

How does private insurance work? Basically, policyholders pay a relatively small, affordable amount into a common "pool" and the benefits of that pool are distributed to the unfortunate few who die (life insurance), become disabled (disability insurance) or develop a serious illness (health insurance). In this way, the financial loss attendant to these events can be mitigated even though the events themselves cannot be prevented.

But not all people are alike. The likelihood of occurrence and magnitude of loss will vary. Some people will apply for large amounts of insurance and others for small amounts. Some will be young and others elderly. Occupations and avocations will modify the likelihood of unexpected death or

illness, as will health enhancing activities such as exercise, proper diet, and nonsmoking. And some applicants will already be in poor health or at known significant risk of developing poor health in the future.

These different factors are evaluated by the insurance company through a process known as "risk selection and classification." The more common term for this is "underwriting." By means of this process, the insurance company determines the appropriate contribution to the risk pool by an individual policyholder.

The fundamental underlying goal of the underwriting process is equity: policyholders with the same or similar expected risk of loss are charged the same. The higher the risk, the higher the premium. The lower the risk, the lower the premium. Note the distinction between equity and equality. With equity, premiums vary by risk; with equality, everyone -- young/old, healthy/ill, and with/without associated factors that significantly increase the likelihood of experiencing an early claim -- would pay the same price.

During the underwriting process, risk classifications are created that recognize the many differences that exist among individuals in order to place applicants into groups with comparable expectations of longevity and health. Although the risk presented by any single individual cannot be determined with absolute precision, if people are assigned to groups with reasonable accuracy and the total number of insured persons is large, then the estimate of the risk of the entire group of insured people is likely to be accurate.

Traditionally, characteristics of importance for risk classification have included factors such as age, gender, health history, physical condition, occupation, the use of alcohol and tobacco, family history, and serum cholesterol. These factors serve to identify individuals that have a greater or lesser likelihood of premature death or illness in the future. Because of this process, costs are held down for the great majority of insurance applicants since premiums more closely match the risks taken on by the insurance company.

Adverse selection, also known as antiselection, is a consideration that is of great importance to insurers. Adverse selection is a well known phenomenon

in which people with a likelihood of loss greater than what they are charged for tend to apply for or continue insurance coverage to a greater extent than do other people. It occurs when applicants withhold significant information from the insurer and/or choose amounts and types of insurance that are most beneficial to themselves. For example, someone with a history of heart disease is more likely to apply for insurance and/or apply for a greater amount of insurance coverage than he would have otherwise done because he knows that he is likely to experience a claim in the foreseeable future. If he fails to mention this important information on his insurance application and the insurer does not otherwise become aware of it, the premium charged by the insurer will be insufficient to cover the risk involved. This premium deficit would be made up by the others in the pool who have paid their fair share.

Adverse selection also occurs if the insurer is not permitted to obtain or use information that is pertinent to the risk being considered. In the example above, the premiums charged would be insufficient to cover the risk involved if the insurer was not permitted to ask the proposed insured and his attending physician about the nature and severity of the heart disease, or if this information could not be used after it had been obtained.

What would happen if the insurance company was unaware of important unfavorable information that was known to the applicant? In these instances, serious errors in risk classification would occur. Certain individuals would receive their insurance at unreasonably low cost. More claims would be filed than were expected. And if a significant number of these risk classification errors were made, the financial status of the entire insurance pool would be adversely affected.

But couldn't premiums simply be increased across-the-board to cover the payment of these unanticipated benefits? Where permitted, an insurer could increase premiums to reflect these revised claims expectations. But this would encourage potential insurance applicants who are at lower risk to either buy from a different seller or exit the insurance market altogether. And with the exodus of the lower risk insureds who were subsidizing the individuals who had knowledge of their unfavorable

risk status -- individuals who had adversely selected against the insurance pool -- a further escalation of premiums becomes necessary. More potential applicants then decide not to apply for insurance.

Eventually, a point is reached in this upward spiral where the desired coverage becomes unavailable on any reasonable premium basis or the insurer becomes financially unsound. This "assessment spiral" phenomenon is not a theoretical possibility. It actually occurred in some companies during the 1880's and early 1900's because of poor risk classification practices.

TYPES OF GENETIC TESTS

Conceptually, genetic disorders can be divided into two broad groups: (1) diseases with a genetic predisposition, and (2) genetic diseases.

Diseases with a genetic predisposition (or a genetic component) are those in which the presence of a gene confers an increased tendency to develop a certain disorder. The disorder may or may not develop depending on a variety of associated personal and environmental factors such as geographic location, diet, exposure to harmful chemicals or toxins, exercise, obesity, tobacco use, heavy alcohol ingestion, and so on. A genetic predisposition is often a factor in the development of common impairments such as cancer, coronary heart disease, hypertension, diabetes mellitus, and epilepsy. Together these disorders are responsible for much of the morbidity and/or mortality that is experienced by the insurance pool.

Genetic diseases are disorders in which the genetic component is so overwhelming that it is expressed in a predictable manner without a requirement for environmental interaction. For example, an individual who inherits the gene for Huntington's disease, cystic fibrosis, or Duchenne muscular dystrophy will eventually develop the disorder regardless of other socioeconomic factors or preventive health measures. Individual genetic diseases are rare compared to diseases with a genetic predisposition but collectively they are an important cause of morbidity and mortality.

Attending physicians will probably begin to use new diagnostic tests that can identify genetic diseases and diseases with a genetic predisposition

shortly after they are developed. As mentioned above, insurers have no current interest in ordering such tests themselves. But although they may prefer to avoid ordering genetic tests, it could be very important that insurers have access to prior test results. Why? If this information were unavailable to the insurer at the time of underwriting, then applicants who already knew via tests performed by their attending physicians that they were likely to experience early death or illness could buy large amounts of insurance coverage at prices that failed to reflect this increased risk. In the aggregate, this could involve disproportionately large numbers of applicants and/or very significant amounts of insurance. The ensuing claims would markedly exceed projected losses and everyone within the insurance pool would suffer.

Consider the following scenario.

Suppose that a man who applies for an individual life or noncancelable disability insurance policy has had a genetic test performed in the past by his attending physician, the results are unfavorable, i.e., the test suggests a significant likelihood of premature death or disability, and the insurance company does not learn about this result. If no other unfavorable risk factors are known in this case, the policy is issued on a standard class basis.

What has happened? Essentially, the principle of equity has been violated. This applicant with an above average claim risk has obtained insurance at standard rates. This situation is very analogous to that of an older person who misrepresents his true age and obtains insurance at the rates of a much younger person. It is important to note that he has not suddenly become a standard insurance risk because he was issued standard insurance. Rather, he is a substandard risk who has nonetheless obtained insurance at standard rates because of a failure of the underwriting process.

Although the applicant would be pleased with this arrangement, the other policyholders would be very unhappy with this sequence of events. True, he currently seems in good health. But his unfavorable genetic test clearly identified a significantly increased risk. And since his insurance coverage cannot be canceled once it has been purchased nor can the premium be increased relative to other policies issued to individuals with similar coverage, it is

likely that he will be paid benefits from the pool that are disproportionate to the premiums he has paid.

PRIVATE AND PUBLIC INSURANCE

Many people have come to expect that private life insurance and, to a greater extent, private health insurance, is an entitlement, i.e., that all citizens have a right to expect that affordable insurance protection will be made available to them regardless of age or health. This expectation is based to a considerable degree on misconceptions regarding the nature of private and public insurance programs. A brief discussion of these two different types of insurance will help clarify their relationships.

PRIVATE (VOLUNTARY) INSURANCE

Participation in a private commercial insurance plan typically is voluntary. You choose whether or not to belong and determine how much insurance protection you would like to purchase. Since all of the funds used to pay future claims against the insurance pool are derived either directly or indirectly from premium payments, risk classification is essential in order to ensure that the premium charged is proportionate to the risk assumed. The potential for adverse selection is very real and an important concern of the insurer. Finally, private insurance companies are businesses that are accountable to their policyholders and stockholders. They must generate a profit for those who have invested in the company. If insufficient premiums are collected, a private insurance company, like any other business in which liabilities exceed assets, will cease to exist.

PUBLIC (INVOLUNTARY) INSURANCE

American society has used private means to fulfill certain general social welfare needs such as payment for health care. But private health insurance has never been a completely adequate or universal method of providing access to the health care system, nor has it been a perfect mechanism for covering all diseases. The poor, disabled, aged, or seriously ill cannot always be covered by private means. For this reason, society has supplemented

private insurance with publicly supported programs such as Social Security, Medicaid and Medicare.

Participation in a public insurance plan is typically not voluntary. You do not choose whether or not to belong nor do you determine how much insurance protection you will have. Rather, participation is mandatory and benefit amounts or entitlements are determined by the law establishing the program.

Since everyone -- good risks, poor risks, even those suffering from a severe or terminal illness -- is automatically insured and there are no options regarding the amount of benefits that will be paid, adverse selection is not a concern. Premiums are charged in the form of income and social security taxes, or so-called "insurance premiums", but they are not and need not be proportionate to the risk assumed. Risk selection is not required and no profit motive exists.

Even given these fundamental differences between private commercial insurance and public insurance, couldn't legislators or regulators simply mandate that private insurers provide coverage -- at rates appropriate for lower risks -- to those individuals who have learned from their attending physicians or an insurer that a genetic test has identified a higher likelihood of premature death or illness? Or, in an action having the same consequences, couldn't insurers be prohibited from asking applicants and their attending physicians for the results of prior genetic tests or ordering their own tests?

There seems little chance that this would work in a private, voluntary insurance industry. This mandated subsidization of unfavorable risks by good risks would be tantamount to an indirect governmental tax levied solely against insurance policyholders and stockholders. The impact of such an action may not appear significant at the outset but its cumulative effects would be dramatic.

Under such a scenario, many potential policyholders -- primarily favorable risks who would be asked to subsidize the higher, underpriced risks, and people with other health impairments such as cancer and heart disease who pay a premium commensurate with their increased risk -- would realize that they are being overcharged or treated unfairly, and choose to not buy insurance because coverage has

now become unaffordable for them.

Why? Wouldn't the premium increase be relatively small? Although such a plan for mandated benefits probably wouldn't result in significantly higher costs at first, premiums would gradually and progressively rise as more and more favorable risks decide not to purchase insurance. The relatively large base of good (standard) risks is progressively eroded, it becomes increasingly difficult to subsidize the poorer risks, and premiums increase again. The situation worsens even more as some companies decide to stop writing this type of insurance coverage altogether since a profit can no longer be expected.

Such a legislative or regulatory mandate would force insurers to provide coverage for a large (because of the effects of adverse selection) group of people at a price that would be insufficient to cover the claims that would occur. These additional costs would be passed directly to other policyholders with a subsequent decrease in insurance affordability and availability.

GROUP INSURANCE

The use of genetic tests by employers is an important topic that will be vigorously debated in the future. Although this is yet another issue not directly related to the use of genetic tests by insurers, it has nonetheless raised concerns that people who are insured through their place of employment (commercial group insurance) may find their coverage jeopardized. A brief overview of the differences between individual and group insurance is provided below in order to address this issue.

For individual life, disability, and health insurance, an applicant applies for whatever amount of insurance coverage that he or she feels is needed (within broad guidelines established by the insurance company). An application form is completed, medical questions are asked, tests may be ordered, and an attending physician's statement may be requested. The premium charged is based on factors such as age, gender, health history, general physical condition, and occupation.

Group life and health insurance is generally divided into two categories: medium to large size

groups containing 10-25 or more employees, and small groups.

Under a medium to large size group life and health insurance plan, an employer buys a single policy for his employees. All employees can elect to receive coverage if they so choose. Benefit amounts are fixed by formula and individuals are normally not subjected to the underwriting process described above with the possible exception of those who choose not to participate in the program when they first become eligible and those who withdraw from the plan and later request reinstatement. Rather, the entire group is underwritten according to factors such as the number of employees, age and gender distribution, area of the country, and prior health care costs for the entire group. Once a rate is established, it is typically adjusted ("experienced rated") on a yearly basis depending on claims experience. If claims exceed expectations, rates increase. And vice versa. With such a large group, it is expected that some workers will be poor insurance risks. But the majority who are good risks tend to offset these few, thus allowing the insurer to offer coverage to the entire group at an affordable rate. Typically, payment by the employer of part of the cost provides adequate incentive for the good risks to join the insured group.

Small group life and health insurance is different. Since these groups do not have the benefit of a large number of employees among whom the less healthy risks can be shared, claims experience is strongly dependent on the health of the small number of individuals within the group. For example, if one individual in the group was already ill or at significant risk of becoming ill in the near future, and the insurer was not aware of this information, then the claims submitted by this one individual could far exceed the claims expected from the entire group. To guard against this possibility, in the absence of underwriting, the insurer would have to increase the premium rates for all small groups. The increased premium rates would induce groups with more good risks not to buy coverage. An assessment spiral much like that described earlier for individual insurance would develop. And if such a practice occurred with any regularity, the cost of insurance to small groups would soon become unaffordable. For this reason, the underwriting of small groups shares

many similarities with that used for individual insurance, e.g., the need for application forms, medical questions, and sometimes tests and attending physician's statements.

What will be the possible effect of genetic testing on group insurance? Approximately 90% of commercial group health insurance and perhaps a similar percent of group life insurance is sold to medium to large sized groups. The employees within these groups are eligible for insurance coverage as a benefit of their employment. There is no individual underwriting or testing of those who sign up for the program when the group plan goes into effect or when new employees begin work. For this reason, the overall impact of genetic testing on group insurance coverage will probably be minimal. For small groups, the ramifications are less certain. The effects may be more similar to those experienced in individual life and health insurance.

GENETIC TESTS AND RISK CLASSIFICATION

Insurers, like the rest of society, are just beginning to consider the impact of genetic testing on the private insurance industry. There are still far too many uncertainties to permit firm conclusions or projections for the future. With this caveat in mind, five points regarding the use of genetic tests to classify risks will now be discussed.

POINT #1. A MAJORITY OF INSURANCE APPLICANTS MAY BENEFIT DIRECTLY FROM THE USE OF GENETIC TESTS

Some critics of the use of genetic tests by insurers to classify risks assume that the results of these tests will generally be unfavorable, the affected applicants will be summarily declined, and insurance availability and affordability will diminish. Such a belief is ill-founded. In fact, the converse may be true. Genetic tests may very well increase the number of individuals who are eligible for insurance coverage due to the superior predictive value of these tests and the resultant improvement in risk classification. Many tests will indicate a very low probability of premature death or illness related to a particular genetic feature. This knowledge may

permit insurance companies to lower the premiums for this quite sizable group of people and increase or at least maintain the same high percentage of people who are granted insurance at standard rates because their level of risk has now been more accurately estimated.

It is true that tests for genetic diseases (as opposed to diseases with a genetic predisposition) will be able to identify some people who will most certainly experience premature death or illness. Knowledge of such test results may lead to adverse underwriting decisions by insurers, i.e., extra premium payments or a declination. But at other times, these tests will offer significant benefits. For example, consider insurance applicants with a family history of Huntington's disease who have no manifestations of this disease themselves. Because it is not yet known if they have inherited the disease, they pose risks to the insurance pool that are very difficult to insure at reasonably low rates. But if a genetic test indicates that they are not carrying the Huntington's disease gene, then insurance coverage could be offered.

POINT #2. INSURERS SEEK TO MAINTAIN A BROAD MARKET

Insurers are acutely aware of the potential problems that might arise if the results of genetic tests were used to prevent significant numbers of insurance applicants from obtaining insurance at affordable rates. There are the obvious public and governmental relations concerns. But financial factors will exert an even greater influence.

Private insurance companies are in business to sell rather than deny insurance. Since this is a very competitive business, insurers have absolutely no incentive to use new tests unless by doing so they can operate more efficiently and offer a lower cost product to the consumer. Even with the advent of genetic testing, the economic necessity of generating new sales will act to ensure that the potential market for insurance products remains as large as possible.

It is worth noting that it was the private insurance industry that was responsible for initiating studies to determine the insurability of individuals with health impairments who had traditionally been unable to obtain insurance coverage. Insurers

concluded that insurance protection could be offered to many of these individuals as long as the risk could be adequately evaluated and priced appropriately.

POINT #3. GENETIC DATA WILL BE EVALUATED IN THE CONTEXT OF OTHER RISK SELECTION PARAMETERS

Genetic test data will represent only one of the many factors that must be considered when insurers attempt to arrive at reasonable estimated probabilities of if and when premature death or illness will occur. This point is in sharp contrast to the mistaken belief that these tests will often be the sole or primary determinants of insurability.

Consider the case of a man who has had a series of genetic tests performed and a heightened risk for the occurrence of a certain type of cancer was identified. Does this automatically necessitate a declination or extra premium payments? No! Many other factors must be evaluated. Is he currently in good physical condition? Are there favorable considerations such as regular physical exercise or avoidance of tobacco and excessive amounts of alcohol? What is his occupation? Is there a history of health problems? How often would such a genetic test abnormality be anticipated in the average person? Is the type of cancer for which the predisposition was identified a common or uncommon cause of mortality or morbidity relative to other illnesses that occur in a large group of insured persons? Does this type of cancer develop so rarely that an adverse underwriting decision may not be necessary even if a significantly increased likelihood of its occurrence has been detected? And how old is he? Has he already passed the age at which the cancer would probably have developed if it was going to occur?

Given all of these considerations, such an applicant who was in otherwise good health might still receive insurance coverage at favorable rates because he is known to be an excellent risk except for a genetically increased likelihood of developing a certain type of cancer. And since he has been alerted to this heightened risk, he can take whatever precautions are possible such as avoiding other factors that may further increase his risk, having regular medical checkups, etc.

POINT #4. ADVERSE SELECTION IS A REALITY

The reality of adverse selection by insurance applicants is apparent from almost any publication dealing with the social, ethical, and economic ramifications of genetic testing. For example, authors discussing the utility of a genetic test to identify the gene responsible for Huntington's disease speak openly about the importance of "acquiring disability insurance" and the need to "buy extra insurance -- before testing." (1). Others write that an important factor in deciding if a test for Huntington's disease should be performed is whether or not the individual is "adequately insured" before the test is ordered (2).

A common theme of critics of the use of genetic tests by insurers is that such a practice would lead to inappropriate risk distinctions among those with genetic diseases (3,4,5). Such comments highlight the mistaken impression that such distinctions by insurance companies are somehow bad or unfair. They also indirectly express the belief that, although it is acceptable to differentiate risks among insurance applicants with a history of cancer, diabetes, or heart disease -- disorders that, like genetic diseases, are usually not someone's "fault" -- by requiring that they pay an insurance premium appropriate for their increased risk, it is unfair to ask the same of people with genetic diseases or diseases with a genetic predisposition.

It is not well understood that differentiating risks is precisely what insurance companies must and in fact are expected to do, i.e., identify good and poor risks and charge premiums commensurate with those risks. In fact, such risk distinctions are the underlying reason why insurance coverage can be offered to so many people at affordable rates.

POINT #5. RISK CLASSIFICATION IS A SOUND BUSINESS PRACTICE

The current levels of insurance affordability and availability are as good as they are because of risk classification and the principle of equity: policyholders are charged equal premiums for equal risks. If insurers were unable to use the results of genetic tests during the underwriting process because "risks

should only be classified on the basis of factors that people can control", then equity would be seriously impaired and private insurance as it is known today might well cease to exist.

But risk classification is not only a matter of fairness. It is also a sound business practice that enables insurers to offer a wide array of insurance products at attractive, affordable prices. With private insurance, people decide if and when they'll purchase insurance, from whom they'll buy it, and in what amounts. Would people be willing to pay more for insurance than what they perceive as their fair share? Would they be willing to make premium payments over and beyond what is needed to cover their own risk so that others at higher risk could get the same type of coverage at a disproportionately low rate?

And where would the line be drawn? If two people of different ages purchase life or health insurance coverage at the same time, would the younger person be expected to contribute the same amount to the pool as the older person? Would a healthy person be asked to pay the same premium as a person who is already ill as a result of a disease that is beyond his control? And if two people have a genetic test performed and one test is favorable and one is unfavorable, would they both be forced to make the same premium payments into a common insurance pool even though the likelihood of an early claim is markedly different? The answer to each of these questions is clearly "NO". In a voluntary insurance market where people can freely choose the timing, seller, and amounts of their insurance purchases, the need for risk classification is more than a matter of fairness. It is an economic reality.

CONCLUSION

In conclusion, I would like to reemphasize a few of the points I made earlier.

Insurers are very supportive of advances in genetic research that will one day lead to earlier treatment and/or prevention of disease. But they have no particular interest in nor enthusiasm for using genetic tests. Their current risk selection practices have generally been accepted by the medical community and insurance-buying public. They

have no desire to initiate new screening tests rife with uncertainty and controversy.

But at some point in the future insurers may be forced to consider using genetic tests if their use becomes standard practice within the medical community. This action would be taken to enhance the risk selection process. But even more importantly it might be necessary in order to provide some protection against the significant adverse selection that would otherwise be certain to occur.

At this time insurers are no more able to answer the difficult questions concerning future use of genetic testing than is any other facet of society. In fact, most of the questions themselves are still unknown. We will continue to study the issues and await further developments. This can be our only reasonable course of action until significant technologic advances are made and the nature and use of genetic testing becomes more apparent.

FOOTNOTES

1. Alan Newman, "The Legacy on Chromosome 4," *Johns Hopkins Magazine*, April, 1988, p. 30-39
2. Sally Squires, "Do People Really Want To Know Their Medical Future: DNA and Destiny," *Washington Post*, October 4, 1988, p. 14-16
3. Joseph Martin, MD, et al., "Predictive Testing For Huntington's Disease With Use of a Linked DNA Marker," *New England Journal of Medicine*, 1988, Vol. 318, p. 535-42
4. Peter Gorner, "A New Genetic Test Can Foretell Agonizing Death: Would You Take it?," *Chicago Tribune*, Aug. 4, 1988
5. Amy Virshup, "The Promise and the Peril of Genetic Testing: Perfect People," *New York*, July 27, 1987, p. 26-34