

GENETIC TESTING, INSURANCE ECONOMICS, AND SOCIETAL RESPONSIBILITY

Patrick L. Brockett,* Richard MacMinn,† and Maureen Carter‡

Our society went into the age of nuclear energy blindly, and we went into the age of DDT and other pesticides blindly. But we cannot afford to go into the age of genetic engineering blindly. Instead we must move into this exciting new era with an awareness that gene therapy can be used for evil as well as for good. As we reap the benefits of this technology, we must remember its pitfalls and remain vigilant.

W. French Anderson, *Scientific American*, September 1995

Genetic testing has the potential to revolutionize medicine. But revolutions can have casualties.

Francis Collins, director of the Human Genome Project, *Newsweek*, December 23, 1996

ABSTRACT

Three major perspectives emerge when the discussion of the implications of genetic testing on the insurance industry commences. One viewpoint, strongly advocated by certain consumer groups and ethicists on the basis of societal responsibility, categorically denies any necessity for connecting the results of genetic testing and issuance of insurance. By contrast, the insurance industry, upon examining the economics and dynamics of participation in voluntary insurance markets, lives in fear of a world filled with asymmetrical information (counter to the axioms for competitive markets), adverse selection (action by the insured as a result of asymmetric information to the perceived economic disadvantage of the insurer), and ultimately even the possibility of potential market failure or insurance company insolvency. An actuarial perspective considering the benefits (to the insurer) of this new genetic information concentrates primarily on the possibility of developing improved quantitative assessments of risk and better calculations of the actuarial present value of future loss costs based on the new statistically significant information gained from genetic testing. The strengths and weaknesses and facts and fallacies of each of these perspectives are examined in this paper, and potential solutions to the ultimate role of genetic testing in insurance underwriting and rate making are considered from the perspectives of the major players in this debate.

BACKGROUND: THE SEARCH FOR CONSENSUS ON DEFINITIONS OF “GENETIC TESTING” AND “INSURANCE”

Framing the platform for any debate logically begins with a consensus on definitions of pertinent terms and the scope of the subject matter to be debated. Lawsuits, for example, begin with a statement of “facts”

or agreed-upon representations. An agreement on the definitions of the terms “genetic testing” and “insurance” would thus be a natural basis for commencing a discussion on the implications of genetic testing on insurance. Unfortunately, the definitions of these terms as used by the disparate parties involved are as diverse as the differing solutions proposed by these

*Patrick L. Brockett, Ph.D., is the Director of the Risk Management and Insurance Program and holder of the Gus S. Wortham Memorial Chair in Risk Management and Insurance in the Graduate School of Business at the University of Texas at Austin, CBA 5.202, Austin, Texas 78712-1177, e-mail, brockett@mail.utexas.edu.

†Richard MacMinn, Ph.D., is Associate Professor of Finance in the Graduate School of Business at the University of Texas at Austin, CBA 6.222, Austin, TX 78712-1177.

‡Maureen Carter is Underwriting Manager at AMIL International, PO Box 200579, Austin, TX 78720-0579.

groups. The lack of consensus on the meaning of “genetic testing” and “insurance” used by the consumer advocates, insurance industry representatives, and actuaries in the National Association of Insurance Commissioners (NAIC) Working Group is indicative of this fundamental definitional schism, as this diverse composite of groups could not come close to agreement.

For example, in a consumer position paper, “insurance” was defined as “a public-regulated activity designed to meet broad community goals” (McGoodwin 1996), a definition that contains no explicit recognition that insurance is an economically based part of the private financial intermediary industry and must serve a variety of economic goals including return on shareholder capital and financial security for the firms involved in assuming the risks of insuring individuals and firms.¹ As a point of reference, the above-quoted broad definition of “insurance” used by the consumer advocates could easily describe the Department of Health and Human Services, whose description of itself is “the government’s principal agency which protects the health of all Americans and provides essential human services, especially for those who are least able to help themselves.”² Consumer activist Ralph Nader goes even further in describing insurance as a vehicle to meet community goals when he asserts that the primary justification for the societal existence of insurance should be the extent to which it actively reduces societal risks (as opposed to primarily serving the function of risk pooling and risk shifting or merely being a financial intermediary).³

The consumer definition of insurance differs significantly from the interpretations of the actuarial profession and the private insurance industry. The actuary views insurance in terms of the probabilistic law

of large numbers and the central limit theorem as “a mechanism for transferring actuarial risk and dealing with it through pooling” (Dicke 1996). The private insurance industry emphasizes that the process of developing and imposing a risk classification system is an essential foundation of the private insurance system. This risk classification characteristic provides an indirect delineation of insurance that emphasizes the *method* used to create insurance pools but may not directly address the actual *definition* of insurance.

In his paper exposing an actuarial position, Dicke (1996) divides insurance into voluntary private insurance markets and social insurance programs. For the former class of insurance activities, he relates that the actuary’s task is to “make sure that assets are set aside to provide for benefits that occur at a later date.” For social insurance as it exists in the U.S. today in the forms of Medicare, Medicaid, and Social Security Disability Insurance, however, benefits are funded out of current payments to the government. They are not the actuarial result of a pooling of funds to provide for future benefits, and there may be little, if any, relationship between the dollars collected from an individual under the name of the program and the benefits promised to the individual from the program (cf. Peterson 1993; Robertson 1997). By definition of the term, they are social welfare programs: services funded by current tax dollars to provide essential human services.⁴ Thus, these social “insurance” programs more closely resemble the Department of Health and Human Services’s description (and the consumer activists’ definition) than the pooling mechanism alluded to in the actuarial definition of insurance, which is directed primarily toward the voluntary market for insurance. In reality, the use of the same term “insurance” to represent both social welfare programs (social insurance) and the economic process of risk shifting and pooling of fortuitous losses with actuarially conceived prefunding methods (as in voluntary private insurance markets) has led to confusion about the “rights” of the individual in insurance contexts (cf. Robertson 1997) and is, perhaps, part of the difficulty in coming to a meeting of the minds on the role of insurance in genetic testing controversies. People from differing perspectives are using the same word to describe vastly different economic structures with differing goals and responsibilities.

¹The Human Genome Project was named one of four items most likely to revolutionize business in the twenty-first century. This prediction was in part due to the ability of genetic testing “to affect the bases of capital accumulation in countries around the world: their pension and life insurance businesses” (Weiner 1992). The genetic information that will subsequently become available will enable closer determination of the likely age of death, and cause of death, making the necessity for a large “contingency reserve” less necessary for the insurer. On the other hand, if insurers are prohibited from using this information in reserve calculations, then larger reserve funds must be accumulated to account for natural adverse selection by the insured.

²Description taken from <http://www.os.dhhs.gov/about/profile.html>.

³See Ralph Nader’s comments in Proceedings of the Symposium “The Distribution System in the 90’s: Insurance and Society in the Decades Ahead,” University of Hartford (West Hartford, Conn.: Barney School of Business and Public Administration, November 1989).

⁴See Rejda (1992) or Peterson (1993) for a discussion of the difference between insurance and welfare.

In a manner similar to that exposed above for the term “insurance,” the literature on the genetic testing/insurance controversy is also plagued with a wide range of definitions of the term “genetic testing.” According to the NAIC Working Group on genetic testing, a “precise definition of genetic testing” does not exist. To complicate the issue further, because the genetic code is deciphered primarily through indirect evidence, it is very difficult to develop a single explicit definition of what constitutes “genetic testing” for all the myriad of applications (Johnson 1996).

In view of the complexity of the issues involved in identifying “genetic information” (as opposed to the traditional use of “family history”) and in view of the fact that there is substantial variability in the genetic information known about any one particular identified disease compared to the next, the NAIC Working Group was forced to create the following lengthy definition:

Genetic screening or testing means a laboratory test of a person’s genes or chromosomes for abnormalities, defects, or deficiencies, including carrier status, that are linked to physical or mental disorders or impairments, or that indicates a susceptibility to illness, disease, or other disorders, whether physical or mental, which test is a direct test for abnormalities, defects, or deficiencies, and not an indirect manifestation of genetic disorders. (ACLI 1996)

In the near future, however, it may become increasingly more difficult to define genetic information and genetic testing. Recent developments in genetic science, for example, reveal that the number of diseases with a known genetic component is increasing rapidly. Future discoveries may very well reveal that the majority of diseases are partially or completely genetically based. Soon there may be a lack of distinction between “genetic” information and other medical information, and between “genetic” tests and other medical tests. There are those who claim a genetic or biological basis for some, or virtually all, physical and mental characteristics, including many behavioral characteristics of interest to insurers.

In dealing with this sensitive definitional issue, state legislatures concerned about protecting against violations of an individual’s “genetic rights” have opted for a relatively restrictive legislative span of control, often promulgating laws concerning a single disease, such as sickle-cell disease. Insurers, on the other hand, have advocated for an “exclusive” rather than “inclusive” principle, desiring instead extremely tight

definitions of what is *not* permissible. Consumer advocacy groups, on the other hand, have tended to consider much broader definitions of genetic testing and have advocated wide prohibitions against the use of genetic testing of any sort for insurance purposes.

In reality, the current controversy about the use of genetic testing in insurance is, to a large extent, a natural outgrowth of a far bigger undertaking, the Human Genome Project. This project, initiated in 1984, is a 20-year, \$6 billion international science project designed to map the entire genetic structure of the human species completely. Basically, the human genetic structure (genome) consists of 23 pairs of chromosomes, which are made up of DNA molecules built from only four different amino acids. These amino acids combine in various sequences to determine the genetic structure of the person; they can be viewed as the analog of a four-letter alphabet whose various permutations and combinations determine all physical characteristics (and some say potentially certain psychological or social characteristics as well) via their interrelations and ordering. In all, the human genome has on the order of three billion total base pairs of amino acids, so this cryptographic exercise of “breaking the human genetic code” like a military code is, indeed, a monumental undertaking. Further complicating the issue of interpreting the human genome (and further complicating the use of genetic tests in insurance underwriting) is that ostensibly some sequences in certain positions have no apparent effect other than “spacing,” while for some characteristics, several distinct sequences appear to lead to this same exhibited physical manifestation or characteristic. Moreover, interactions of sequences in different parts of the genetic code can influence exhibited characteristics, and environmental and behavioral conditions can “trigger” or “inhibit” the exhibition of certain traits, making the explicit actuarial linkage of specific disease-related insurable expenses to identified genetic markers even more tenuous in many (but certainly not all) cases. Moreover, since the prevalence of the suspect genetic sequences in both the “nondiseased” and “diseased” populations are as yet undetermined, the appropriate calculation of such risk factors by actuaries (via Bayes’s theorem) is fundamentally uncertain in usefulness.

Nevertheless, tremendous headway has already been made in mapping the human genome; the genome project is ahead of schedule; and certain chromosomes have been mapped (for example, the location and function of the various genetic positions have

been flagged, and links have been established with individual characteristics and diseases). In theory, individuals could be screened for a multitude of diseases by undergoing genetic tests. Scientists have already mapped most of chromosome 21 (Hood and Keveles 1992), and more than 4,000 disorders have now been identified and linked to specific sites on specific chromosomes. The current cost of genetic testing, however, makes the issue of widespread screening not feasible at the moment. Nevertheless, individuals with symptoms or histories of certain identified diseases *could* be genetically tested if it were cost effective from the perspective of the entity doing the test (the insurer, for example) to increase the accuracy of ascertaining the conditional probability of the person's having the increased health care expenses given the genetic test results (that is, as opposed to calculating this conditional probability of the person having the increased costs given only the fact that the person had a symptom or a family history of the diseases).

The public policy issues of having a large set of "false positive" pronouncements in mass screenings with a small relative frequency of the abnormality in the population cannot be ignored either. Via the Bayesian theorem, if the frequency of the characteristic in the population is extremely small, then even if one has a genetic test with both a very high sensitivity and a very high specificity, it may still be the case that the conditional probability that one has the disease given that one tests positive is very small. For example, suppose that a certain rare disease occurs in 1 in 10,000 individuals from the population. Suppose further that a genetic test for the disease correctly identifies 99.9% of the people who have the disease as "positive" and also correctly signals 99.9% of the people who don't have the disease as being "negative," seemingly a remarkably accurate test indeed. Still, the conditional probability that a person has the disease given that he or she has a positive test result is (via the Bayesian theorem) only 0.09, or only about 1 in 11 positive tests correspond to people with the disease. Put another way, in a mass screening of a population of 100 million people, 10,000 will have the disease, of whom 9,990 will correctly test positive, and 99,990,000 will be disease free, of whom 99,990 will test positive (and the remaining 99,890,010 will correctly test negative). This gives an odds ratio of about 11 to 1 that a person who tests positive will, in fact, *not* have the disease. If you used this "remarkable" genetic test to mass screen or rate candidates for insurance or employment, then there are high odds of making a mistake and falsely rejecting a good

applicant. Given the consequences of being rejected for health insurance in the U.S., this error rate is rightfully considered as unacceptable by consumer activists.

Ideally, in the future, each of these genetically based diseases will be curable by genetic engineering, for example, the introduction of genetically altered viruses into defective cells to substitute their DNA structure for that of the invaded cell. These viruses could be used to carry a new "correctly coded" DNA into the diseased cells. Such genetic engineering portends the ability to alter the genetic composition of an individual and actually cure genetically based diseases. For example, one might have the option of "curing" Down syndrome or Huntington disease rather than facing the option of aborting a chromosomal-defective fetus.

As the actuary Arnold Dicke (1996) points out, the various definitions of insurance outlined previously are not necessarily in diametric opposition to each other, and similarly, the descriptions of genetic testing are not on the same continuum. Still, these definitions of "insurance" and "genetic testing" are not yet close enough for a consensus and do not form a solid basis for further mutual understanding by the parties involved. An analysis of the history of insurance and genetic information is reviewed next to ascertain whether it is possible that a proposed solution can evolve from this perspective.

HISTORY OF MEDICAL INFORMATION AND INSURANCE

For years, insurance companies have attempted to place insureds into homogeneous subgroups wherein each insured pays a premium or price that closely reflects his or her *ex ante* expected losses. "Classification" in insurance is the process by which this is accomplished. In practice or social discourse, this classification process might be labeled as involving either "fair" or "unfair" discrimination of the insured, depending upon the particular context of the classification scheme being used and the ethical values of the observer. The *process* of discriminating between risks (using classification), however, has positive benefits from the perspective of both the insurer and insured in that it promotes the equitable distribution of loss costs and helps to make insurance more attractive and affordable to all classes of insureds (because the price charged is relatively close to the expected losses of an insured risk), reducing the necessity for

individuals to maintain large “contingency” funds to handle fortuitous losses should they occur.

The concept of risk classification and discrimination (the term “discrimination” is used here in a value-neutral dictionary definition of the term) as used by insurance companies, however, is often misunderstood. For example, Carl B. Feldbaum, president of the Biotechnology Industry Organization, the nation’s leading biotechnology trade organization, argues that genetic information should not be used to “discriminate unfairly” in insurance and several other cases. According to Feldbaum (1996), “tough sanctions, even criminal penalties, should be considered to keep our most intimate genetic information out of the hands of those who would use it, not to treat individuals with diseases or to develop new medicines, but to discriminate.”

From the insurers’ perspective, a fundamental purpose of insurance classification schemes for distinguishing among potential insureds (discriminating) is to allow them to charge the insured a premium proportional to the expected cost or the risk that he or she is perceived to bring to the insurer. This tie of risk to premium rate is unchallenged in many lines of insurance. For example, in fire insurance, it is noncontroversial to charge higher rates for wood frame structures than for brick or stone structures; in life insurance, it is logical to charge higher premiums to smokers than to nonsmokers, and so on. In automobile insurance, as well, there is even evidence that the consumers strongly agree with the notion that “people should pay different rates for car insurance based upon the degree of risk they represent to the insurance company.”⁵ While the same argument might logically be applied to the setting of premiums for health insurance and the use of genetic information, there appears, however, to be a different perception of the desirability of the above quoted statement when the words “health insurance” are substituted for “car insurance.”⁶

⁵In a March 1991 poll conducted by the Gallup Organization, individuals were asked the extent of their agreement with this quoted statement on a one-to-four scale, with one denoting strong disagreement and four representing strong agreement. The 1,000 persons polled had an average score of 3.36 on this, which indicated strong general agreement with the statement. See *Best Review* (Property/Casualty Ed.), 91, no. 11 (March 1991), p. 12, for further details.

⁶Results of surveys taken by the first author in undergraduate and graduate risk management classes over several years show a significant disagreement with the statement concerning health insurance risk. Since business school students studying insurance are probably

When there is suppression of information, as would occur, for example, if insurers were forced by law to ignore genetic information in classification, and if the insurers were forced to charge the same rate to insured persons who are known to have different expected loss costs, then the insurance pricing not only might be viewed as “unfairly discriminatory” to the group of lower-expected-cost persons but also would encourage moral hazard and adverse selection against the insurer. The financial effects of these adverse incentives ultimately drive rates upward and might even threaten the solvency of insurers.

Distinguishing between risks with respect to expected loss costs (and grouping accordingly) allows a reduction in the amount of financial cross-subsidization between various groups of insureds in an insurance pool. That is, high-risk (or high-expected-cost) insureds are distinguished from lower-risk (or lower-cost) individuals in a pool and charged higher prices than are low-risk insureds. Each insured then pays his or her own fair share of expected future loss costs for the insurance pool, as is normally considered to be equitable.⁷ The situation of ignoring (for pricing purposes) the level of a pertinent variable that has been shown to be significantly related to the expected losses is tantamount to a wealth transfer (subsidization) from the lower-risk individuals (who are overpaying according to best actuarial estimates of their prospective expected losses) to the higher-risk individuals (who are underpaying according to best actuarial estimates of their prospective expected losses).⁸

more favorably inclined toward the insurance industry position than the general public, this result indicates a strong and widespread attitude in opposition to classification in health insurance.

⁷In this context the notion of “fair” corresponds to the relationship between costs (to the insurer) and benefits (paid by the insurer) and is closely related to the notion of equitable. Other perspectives relating the concepts of “fair” to absolute relationships involving human value, dignity, and ethics are, of course, possible as well. As pointed out in a personal communication by James Hickman, it is interesting that the famous correspondence between Pascal and Fermat that initiated the modern mathematical concepts of probability theory arose from a consideration of the problem of how to distribute the pot in an interrupted gambling game “fairly”.

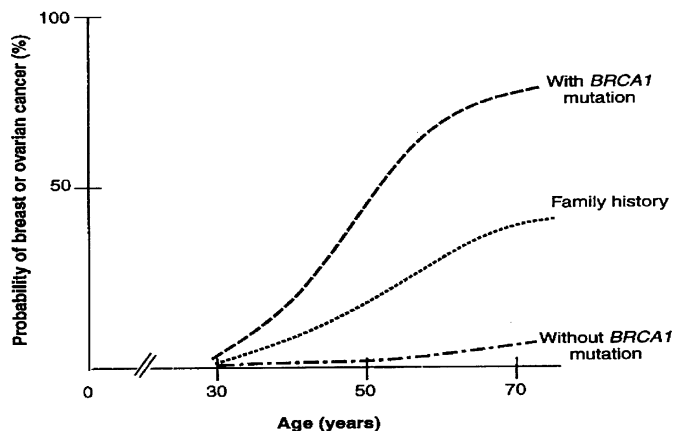
⁸If such a wealth transfer were deemed to be socially advisable (by some social policy decision maker), the question still arises as to whether using insurance as a wealth transfer mechanism is ethically appropriate. It may also be infeasible since low-risk insureds would drop out if the cross-subsidization becomes too great. A great political advantage of using the insurance mechanism, of course, is that it is not apparent to the public who might not approve of a “hidden tariff” to the lower-risk insureds to subsidize high-risk behavior.

According to McNamara (1978), “discrimination” is simply the act or practice of making a distinction categorically rather than individually, and since insurance functions by substituting group costs and losses for individual costs and losses, insurance is tautologically discriminatory (where the word “discrimination” here is taken in its dictionary and not emotionally loaded sense). On the other hand, McNamara designates discrimination as being “unfair discrimination” when this categorical distinction is not justified by the facts (for example, actuarial or statistical relationships between the classification variable’s level and ultimate loss costs). Insurers generally hold that a *statistical* justification provides a sufficient defense for using a classification scheme; that is, the use of a particular variable by a company in a rate-making structure does not constitute “unfair” discrimination provided individuals with differing levels of the variable have statistically and significantly different prospectively projected loss costs. Indeed, if two people having different levels of the variable do have different expected loss costs, then it could be argued that it would constitute unfair discrimination against the lower-risk person *not* to use that information in classification. That is, it would be unfairly discriminatory to charge two individuals the same price when they have different expected loss costs. In a similar vein, a lack of proportionality between prices and average expected loss costs among classifications is viewed as constituting “unfair discrimination” by Williams (1969).

Figure 1, taken from Ponder (1997), exhibits the statistical differences between the information supplied by knowing family history, and genetic test results for the BRCA gene (an average value ignoring whether or not the individual has a family history) as compared to (average) background population rates for breast cancer (ignoring whether or not an individual has a mutated BRCA1 gene). As can be seen, the predictive accuracy of using the more definitive information set can affect expected loss costs (and hence premiums). Actuarially such increased information can be incorporated into the premium calculation by using the information theoretic methods outlined in Brockett (1991), Brockett and Song (1995), or Brockett et al. (1996). Once the new pure premium has been calculated, the charge is then reflective of the known risk.

There are legislative constraints on which variables can be used as the basis of rate classification. In these situations, in addition to mandating a wealth transfer

Figure 1
Statistical Likelihood of Breast or Ovarian Cancer for 30-Year-Old Woman up to Age 70
(Taken from Ponder 1997)



from the “overcharged” low-risk group to the high-risk “undercharged” group, the constraints can also lead to market dislocations as insurers attempt to control the adverse selection by other means, such as more stringent underwriting. Illustrative of this assertion is the automobile insurance market, where it has been found that states with the largest involuntary or residual markets are also the states with the most restrictions on rate classification (cf. Harrington and Doeringhaus 1993).⁹ These involuntary markets for high risks also tend to run up large deficits, and the economic reality is a further transfer of the cost of subsidizing the higher-risk groups onto society, taxpayers, and other insurance purchasers in the voluntary market to the benefit of the high-risk drivers themselves. The lesson to be learned from these markets in the context of genetic testing is that by restricting the insurers’ use of genetic information for underwriting purposes, a wealth transfer from the lower-risk to the higher-risk group is created. While this may be desirable from a societal perspective, it

⁹The involuntary or residual markets are composed of those persons who are required to buy insurance (i.e., automobile insurance or workers’ compensation, for example) but who fail to meet the underwriting guidelines of the primary insurance markets. These “high-risk” individuals are the residual, after the primary market has made its selection. These are the “assigned risk” automobile drivers, for example, who must be allocated to an insurer (involuntarily) or put into a state-run automobile insurance fund. They are the “automotive driver” analogy to the high-risk health insurance population.

must be debated whether insurance is the most appropriate mechanism to achieve this wealth transfer. It may be relatively uneconomical in that there may be other wealth transfer mechanisms with lower administrative costs.

The “equitable” nature of charging each person according to his or her perceived risk costs sometimes comes into conflict with the social concerns or moral imperatives expressed by society at particular times. In these cases, society, through laws or regulation, constrains the open competitive market choice of insurance classification variables. For example, there is actuarial evidence showing statistically significant relationships between losses and race in certain lines of insurance. As a society, however, the U.S. is very concerned with charging higher costs based (even in part) on race. For this reason antidiscrimination laws have increased the restrictions on classification and underwriting variables, and legislators and regulators have also imposed restrictions on the competitive market determination of rates for certain lines of insurance in various states. Other examples of regulatory restrictions on classification variables abound in various different lines of insurance.

While certain potential classification variables such as race or ethnic or national origin are not legal to use in rate making because it has been deemed to be socially unacceptable to use such information, it is, in fact, debatable as to who gains and who loses in the wealth transfer inherent in a mandated suppression of information. It has simply been deemed to be socially unacceptable to discriminate along these lines, as a matter of public policy. If these restrictions were repealed, for example, then certain racial groups or a certain sex would pay more for life insurance, less for life annuities, more for health insurance, and so forth. The financial impacts would be differential across races, and economic realignment would ensue.

CURRENT INSURANCE MARKET STATUS

The majority of life insurance policies are purchased individually. Some employers provide small policies as employee benefits, but this is a small percentage of the total life insurance sales. In contrast, 85% of health insurance policies are group policies. In most cases, these policies are provided by employers. The other 15% of Americans who have health insurance are covered by private insurance policies or governmental plans including Medicaid for the poor and Medicare for the elderly. The remaining 34 million Americans are not insured. While most hospitals will provide

emergency care for such individuals, preventive and nonemergency care must come out of their own pockets.

With respect to genetic aspects of insurance:

- 14 states have health coverage regulations (including two with legislation pending)
- 7 states have life coverage regulations
- 2 states have disability coverage regulations
- 2 states have long-term care coverage regulations
- 5 states have sickle-cell trait coverage regulations
- 2 states have genetic discrimination regulations
- 1 state has hospital and medical coverage regulations.

SOCIETAL CONCERNS

Privacy Rights

One issue that concerns ethicists and consumers is the privacy of genetic and medical information. Privacy is valued by citizens across the world whether they are able to exercise the right to privacy or not. Not surprisingly, the legislative solutions that have been put forth in the U.S. have strongly protected an individual’s right to privacy.¹⁰ A California bill that passed in 1995, SB 1020, contains a series of provisions barring the disclosure of the results of genetic tests to a third party to safeguard patient confidentiality. This bill applies to health care service plans, life and disability insurers, self-insured employee welfare benefit plans, and nonprofit hospital service plans. In the event that the genetic results are made available, this same bill prohibits health insurers from offering separate coverage to people whose genetic examinations indicate a susceptibility or propensity for disease, such as diabetes, cerebral palsy, or muscular dystrophy. The California bill sets up a series of fines ranging from \$1,000 for first offenses to \$100,000 for repeat offenders on agents and carriers that violate the new rule (“Cal. Bars Use of Genetic Tendency Data,” 1995).

The lack of privacy of medical information would startle most Americans. In fact, no federal law protects the confidentiality of medical records (Forbes 1995). To remedy this situation, Senator Bob Bennett,

¹⁰Ironically, the privacy of medical information gathered by the U.S. government is strongly protected, but medical information gathered by private sources (such as insurers, employers, hospitals, adoption agencies, doctors, the Medical Information Bureau, etc.) has very few protections or recourses if erroneous information is present.

R-Utah, sponsored the Medical Records Confidentiality Act in 1995. This federal bill proposed that all holders of medical records get patient consent before disclosing any personally identifiable data. Currently, consent is not required for disclosures related to life-threatening emergencies, legal investigations, and bona fide public-health research. Privacy advocates criticized the proposed federal legislation for not going far enough, and bill opponents said the exceptions allow "too much trafficking in medical records." Even though the bill received bipartisan support, the above-cited double-sided opposition caused the bill to fail. According to health care author Eric Weissenstein (1996), the failed federal legislation proves that protecting patient medical records is "far more complicated than it appears at first glance."

When the implications of genetic testing on insurance are considered, one question that must be answered is, Who should be allowed access to an individual's genetic information? Determination of the point at which it becomes an invasion of privacy to ask questions concerning characteristics of the potential insured is a legitimate societal issue, especially in genetic testing. In life and health insurance, testing for the HIV virus and obtaining information about participation in hazardous hobbies or occupations for classifying risks provide examples of using personal attributes or characteristics for classification purposes because of their economic significance in predicting expected loss costs.¹¹ The cost effectiveness of utilizing these variables in rating or underwriting decisions has, however, changed over time, as has society's view of what constitutes an invasion of privacy.

The debate on the type and amount of information an insurer can receive about an insured is crucial to the genetic testing/insurance issue. Although insurance companies usually ask potential insureds underwriting questions about family history of disease, and possibly give physical examinations, these provide only gross delineations of genetic propensity (gross enough to create substantial uncertainty among the applicants as to existence and timing of possible losses so that a viable risk pool of similarly situated individuals can be created involving fortuitous losses among the members). In addition, companies also have other

sources for medical information. For example, the Medical Information Bureau (MIB) in Westwood, Massachusetts, keeps briefly coded health resumes for millions of Americans (about 17,000,000 records are kept, but there is some duplication of records due to the use of alternative names, such as James and Jim, for the same person). Most of the information is from insurance applications and physician records on patients, but, according to Blakeslee (1990), the practice of physicians furnishing medical records to insurers based on authorizations in insurance application forms threatens the whole notion of patient-physician confidentiality. Other insurance member companies can also have access to medical records contained in the MIB, in order to help their underwriting investigations and to detect fraud.

Consider next a scenario in which an individual takes a genetic exam in order to ascertain whether there are any preventive measures that might be taken for a suspected disorder. In such a situation, who should have access to this information? Family members, twins, insurance companies, and employers are all potential candidates for using such information. Some have argued, however, that the individual's right to privacy is the single most important consideration; the effects of the genetic disorder upon people other than the genetically tagged individual must be placed secondarily to the effect upon the individual.

Illustrative of the above controversy, Michigan State Representative Matt J. Dunaskiss asked Attorney General Frank J. Kelley whether an employer's worker's compensation representative and insurance representative may have unlimited access to employee-patient medical records maintained in a medical clinic owned by the employer where the employee-patients have filed claims and are seeking worker's disability compensation for the injuries. Kelley's response was:

It is my opinion . . . that the worker's compensation or insurance representatives of an employer may have access to medical records of an employee-patient examined and treated in the medical clinic of the employer for an injury sustained during the employment, but information secured and placed on the medical records by the attending physician or physicians which is not relevant to the claim of the employee-patient for worker's disability compensation may not be disclosed without the waiver of the employee-patient. (Selected Attorney General's Opinions, Michigan 1992)

Kelley's opinion clearly indicates that he believes insurance companies should have access to only the

¹¹ Another relevant issue related to the use of these variables in insurance underwriting is the extent to which the variables themselves are controllable by the insured. In the case of many accepted underwriting variables, they are controllable but not in the case of using genetically related underwriting variables. This matter is discussed subsequently.

relevant medical records needed to determine claims and not necessarily to all medical records for use in underwriting purposes.¹²

Also note, however, that the primacy of the individual's right to privacy is not accepted by all, and, in fact, this "right" is routinely rejected in many contracts that are reciprocal financial arrangements between parties wherein the potential for exploitation of one party by another exists because of information asymmetries. SEC regulations, as well as insurance company medical examination application forms, are illustrative of this alternative perspective rejecting the unilateral right to privacy. The counter-argument is that the people putting their money at risk (investors in the SEC regulations and insurers in the medical examination context) have the right to know the same risk information as those on the other side of the financial transaction.¹³ Illustrative of one taking this stance is Harvie Raymond, director of managed care and insurance operations at the Health Insurance Association of America (HIAA) in Washington, D.C., who contends that "he who assumes a risk should have the opportunity to evaluate that risk" (Shulman 1995). In fact, with information disclosure, markets become more efficient and risk premiums decline. Popular examples of this are truth-in-lending disclosure requirements, mpg stickers for automobiles, energy efficiency ratings for appliances, and the role of crop-reporting services in improving the efficiency and decreasing the risk premiums in commodity markets.

Many medical privacy advocates defend their restricting position because of the effect that the knowledge of ailments can have on insurability in a voluntary insurance market. For example, most insurance companies are highly reluctant to insure Alzheimer patients, despite the appreciable life span after diagnosis. Some companies will consider people with Alzheimer in the early stages at higher ratings, but most companies decline these people as well (Goldstone 1993).

Another issue is whether the medical profession or the insurance industry (or any other entity involved

with medical information) is, in fact, keeping confidential information secure. According to the insurance industry, they have been a strong guardian of these medical secrets. Are the leaks in medical confidentiality due to insurance industry policies, or do other problems in medical information confidentiality need to be addressed? While this appears to be a side issue for the discussion of genetic information and insurance, it can be the default problem that, if it does not receive the proper attention, can be responsible for jeopardizing future discussions on the consideration of genetic testing to set insurance rates. The possible implications of invading medical privacy and the difficulty of ensuring medical privacy compound the problem of genetic testing and insurance. While the establishment of a strict and enforced confidentiality code for medical information by the insurance industry will not magically assure the inclusion of genetic information in insurance rate making, a lack of proper confidentiality management will definitely prevent insurers' access to genetic records because of legislative and societal dictates on the importance of privacy for this most intimate of personal data.

Insurer Concerns About Adverse Selection and Solvency

Insurers point out that genetic information is currently being used in the form of cholesterol tests, height and weight measures, and family history questions. From their perspective, the elimination of use of genetic information would necessitate fundamental structural changes to the market, result in a socialized risk or public insurance program, and result in the insured having more information than the insurer. In being denied access to genetic information, the insurance industry is concerned about adverse selection and its role in the solvency of an insurance company. In this context, the term "adverse selection" is defined as "the process in which the exercise of choice by insureds leads to higher-than-average loss levels since those with a greater probability of experiencing a loss are most likely to seek that kind of insurance" (Rejda 1992).

Individuals who have been genetically tested and whose results show a predisposition or a high probability of obtaining a disease can be expected to be more likely to purchase insurance. The occurrence of adverse selection can be reduced or prevented by allowing the insurer the appropriate use of all pertinent information known to the insured about potential loss propensity for the purpose of insurance classification.

¹²This opinion should not be stretched too far, however, since it concerns worker's compensation insurance, which is a mandatory coverage in every state except Texas, and because experience rating of worker's compensation premiums limits the opportunities for antiselection.

¹³Again, it is clear that if one views "insurance" as an economic institution as opposed to an instrument of social policy, then one is led to different positions on this issue.

The adverse incentives associated with charging the same premium to persons known (to themselves) to be relatively higher or lower risk than the pool into which they are put occurs because the lower-risk individuals, who are subsidizing the high-risk individuals, are motivated to drop out of an insurance pool or find alternative means of preloss or postloss financing. As these low-risk insureds drop out of the insurance pool because of being charged what they know to be a disproportionate share of the pool's expected losses, the only insureds left in the pool will be the high-risk ones. In fact, the high-risk individuals (or those who know they are high-risk because of having had genetic test results that were not communicated to the insurance company) will also simultaneously be disproportionately motivated toward purchasing insurance in larger quantities and will eventually constitute a larger portion of the risk pool. This will then necessitate that even higher premiums be charged, starting the cycle again.

This adverse selection of insured individuals can lead, in severe circumstances, to a complete market failure if the high-risk insureds differentially choose to purchase insurance, changing the risk pool from one in which the losses can be construed as occurring "independently and identically distributed," and hence allowing the invocation of the statistical law of large numbers, to one involving a mixture of several distributions having no single "fair" premium possible. The insurer would necessarily assume the worst and set premiums for the pool according to the worst risks, and this could cause rates to rise for all who choose to buy insurance. Illustrative of this point is the discussion on a bill by two Minnesota lawmakers that would prohibit insurers from using genetic testing as an underwriting tool in Minnesota. This bill was strongly contested by the insurance industry. Al Parsons, president of the Insurance Federation of Minnesota in St. Paul, even called the bill "anticonsumer" because "if carriers are not able to have access to people's medical background to classify risk . . . over time the price of the product is bound to go up to reflect the carriers' experience" (Cox 1995).

Thus, using all available information on the estimation of the prospective losses associated with the risk in insurance classification helps maintain the viability of competitive insurance markets as risk transfer and pooling mechanisms from the perspectives of both insurer and insured.

If insureds who were *known to have* dramatically different costs were charged the same rate, the

insurance market might collapse.¹⁴ This has, in fact, occurred in some life-contingent insurance markets. For example, an early form of life insurance in the 1800s was provided by "assessment societies," groups (often fraternal organizations) that would agree to pay death benefits to members. As members died, the surviving members of the group were assessed equally for the death benefit costs. As the members aged, deaths (and assessments) came more frequently, making recruitment of new, younger members more difficult. Then, as the size of the group decreased because of younger, lower-risk individuals choosing not to participate, the assessments became more costly. Eventually the cost of membership became too great for all, and the entire plan collapsed.

The same situation could occur in *any* circumstance in which members are charged the same premium rate but are known to bring different expected costs to the group. That is, lower-risk individuals might choose not to participate in what they perceive as an economically unfair arrangement wherein they subsidize higher-risk members. The withdrawal of the lower-risk members, and the tendency for the individuals who know themselves to be higher-risk to view the arrangement as a "good deal," could eventually leave only high-risk individuals in the plan. The ever-escalating rates for membership caused by escalating percentages of high-risk members could finally cause the scheme to fail entirely. A solution to this "adverse selection" problem is to charge each participant according to the best estimates of his or her expected costs.

When an individual applies for insurance, he or she is placed in a pool of insureds with matching health characteristics and charged a premium based on the expected costs. If the insured and the insuring company both know the genetic testing results, this individual is charged a premium that matches the expected costs. If only the insured knows that he or she will contract (or has a higher-than-normal probability of contracting) a disease and the insurance company does not have this knowledge, then the insured will be incorrectly placed in a pool with individuals having much lower expected costs and consequently lower

¹⁴If the insureds were not known to have different prospective loss expectations, then this collapse would not occur since no "arbitrage" of this information to the detriment of the insurance company and risk pool members is possible. Before genetic tests were available to distinguish risks, people were charged the same rates without regard to the genetic test results. It is only *after* the information is available to some that its suppression causes the problems discussed here.

premiums. In this case (and in other similar cases), the insurance company's losses for this subclass of insureds will be higher than expected. Premiums to everyone in the group will increase to cover the loss. The resulting higher cost of insurance will then encourage healthier people to drop out of the pool. When the pool is smaller, the expenses of the pool will be spread among fewer, higher-risk people, and the premiums will once more increase and the cycle will repeat itself. If more individuals are inappropriately matched into a pool, the combination of the adverse selection process, greater losses, and smaller pools threatens the solvency of that book of business of the insurance company.

As an illustration of the adverse selection problems that can occur, consider the case of the health care "reform" bill implemented by the state of Washington. With "guaranteed issue" provisions included in the bill, insurers were required to provide coverage to all who applied. In addition, Washington required "file and approval" for product pricing, had no incentives in place to encourage insurer participation in the health insurance markets, and included no risk-sharing mechanisms. To compound this problem, a 90-day open enrollment period was implemented to begin the program. This led to disaster for numerous insurers. In one case a particular insurance company reputedly enrolled a large number of AIDS patients as clients, and rapidly lost millions of dollars on its guaranteed issue business in Washington. When this company attempted to cancel this block of business, a class action lawsuit was filed by 8,500 policyholders. The economic viability of the insurer as a competitor in a capitalistic market can be threatened when business decisions cannot be made on the basis of economic value to the firm.

As another illustration, in New Jersey after another "health care reform" bill was passed, one insurer entered the market in 1993 and rapidly enrolled more than 50,000 individuals, many of whom had serious medical conditions. While its initial pricing resulted in a \$1.6-million refund to policyholders for 1993, claims escalated to a breakeven in 1994 and a \$27.2-million loss in 1995. Even with several 50%+ rate increases, this company has still retained a book of 19,000 policies. A review of this business has revealed that 1.6% (or approximately 300 policies) generate in excess of 36% of all claims.¹⁵ If this process were to

be replicated at a number of insurance companies, then the economic viability of the entire industry with respect to this type of coverage could be in danger.

Insurers want a "level playing field of knowledge" because they fear that applicants who have been genetically tested by their physician (or by using home testing kits such as those for AIDS screening) can use this "extra" information to buy insurance at an unfairly depressed rate. According to James A. Mitchell, the chairperson of a 1991 CEO task force that was set up by the ACLI and the HIAA, the life insurance CEOs "can live in the current environment, or we can live in an environment with a lot of genetic testing as long as we have the same knowledge as the applicant," adding that he personally was "indifferent to where on the spectrum we are" (Crosson 1994).

Insured Concerns

Consumer groups advocate the prohibition of genetic testing for any type of insurance. They believe that the actuarial tables already reflect the probabilities that the insurance companies need and that individuals would avoid treatment to protect insurability. Since many diseases are treatable, the presence of a genetic disease does not necessarily signify poor general health. Therefore, it is argued, genetic tests would not serve value. Genetic makeup, they maintain, should be considered as similar to certain other legally barred classification variables such as race, age, sex, disability, and place of residence (cf. McNamara 1978). In general, there are certain commonalities in consumerist concerns about the use of these variables. These concerns about an economic free-market determination of risk classification variables center along the following properties of the variables:

1. Controllability of the classification factor by the insured
2. Causality of the factor's relationship to ultimate losses
3. Credibility of the data upon which the classification factor's relationship to ultimate losses has been determined
4. Privacy issues regarding how much information about a person an insurance company should be able to use
5. The complaint that individuals are being treated as a group rather than having their premiums determined solely on the basis of their own particular individual characteristics (such as driving record in automobile insurance, construction material in building fire insurance, healthy lifestyle characteristics in health insurance).

¹⁵ Telephone interview with Scott Geske, Senior Individual Health Actuary, Time Insurance Co., September 1996, conducted by Chris Sapstead, University of Texas at Austin.

We consider each of these topics in turn.

The Controllability of the Classification Factor by the Insured

The major concern of opponents of the use of genetic information in the underwriting of private insurance involves the controllability of the classification variables by the insured. This concern is consistent with the noneconomic notion that insurance not only should be a financial intermediation technique spreading or pooling fortuitous losses among individuals or across time, but also should be a vehicle for actively reducing loss costs to society by providing incentives for increased safety. Advocates of this view argue that if the classification factors used cannot be controlled by the insured, then the insured is supposedly being charged a larger (or smaller) premium because of characteristics beyond his or her control, and the insured cannot reduce costs by any loss-control actions. This argument is further compounded, in the U.S., by the fact that one often has no recourse, in the voluntary private health or life insurance market, if one is deemed an unacceptable risk for insurance. Since, in the U.S., access to health care service is often connected to access to health care financing through health insurance, the notion that “health care is a right” translates into a statement that “health insurance is a right.” Consequently, being denied this “right” for reasons beyond your control is considered by some to be “unfair.”

The counterargument to this stance is that there is really no reason to believe that a variable must be controllably related to a loss before it is a valid or useful predictor of expected future loss costs in an economically based business. For example, sex is not a controllable factor, and yet, because of statistical evidence, it might be logically and appropriately used as a rating factor in maternity benefit insurance, life insurance, and perhaps even automobile insurance. Similarly, location is fundamental in pricing insurance covering hurricanes or earthquake insurance and might not be considered controllable in many instances. Moreover, we have already found it acceptable for society or government to group people together on the basis of uncontrollable factors for many different (noninsurance) reasons. Driver’s licenses require the attainment of a certain age; certain professional sports are restricted according to sex of the participant; school attendance is determined by residency or locality; and the costs of attending college are dramatically affected by the state of residency (cf. Cripe 1992). The issue of whether an individual is selected

for marriage, military service, employment, or college admission can have social consequences far greater than their selection or rejection for insurance.

While not being controllable by the individual, the genetic test results can often be found to be (statistically) significantly related to prospective loss expectations of the insured. An individual’s lack of control over his or her own genetic structure does not negate the economic significance of this same genetic structure’s relationship to prospective loss determination involved in insurance. The test of validity of an insurance rate-making classification variable in a competitive economic market is its ability to cost effectively aid in the estimation of expected future loss costs, not necessarily its ability to stimulate societal risk reduction. If there is a legitimate societal goal of reducing risks of this type that does not align with the classification scheme so used by insurers, then there may be more effective and more directly related techniques available—such as tax incentives—to accomplish these goals. If a “safety net” were created, analogous to “assigned risk plans” provided for high-risk automobile drivers who “need” insurance, then the pressure on insurers to underwrite based only on controllable variables would be lessened.

The Relationship of Causality to Potential Losses

The causality of a classification factor’s relationship to ultimate losses is another frequently used litmus test for determining the acceptability of a classification factor for underwriting. However, many factors such as sex, age, and location, which are used to project future expected losses, do not have a *causality* link to those future losses in the sense that there is a direct logical link apparent between the various levels of the classification variable and the levels of loss. It has been argued that until such causal linkages are established, the insurance industry should refrain from using these variables since they “unfairly” discriminate among the insureds. In this situation, we emphasize that the notion of apparent causality is also a statement about the *level of understanding of the phenomenon by the observer*, as well as an empirical statement about the behavior of the phenomenon at different levels of the classification variable. For example, to some people, the appearance of lunar eclipses is a remarkably random event, while to other knowledgeable observers the appearance of an eclipse is causally related to other planetary movements and is completely predictable. In a similar manner, certain diseases that were previously believed to strike certain

insureds randomly have now been causally linked to genetic origins. Moreover, the notion of “unfair” is also dependent upon whether one is perceived to be “undercharged” or “overcharged” by the process under examination.

At any rate, causality in the context of insurance can best be described as increasing the *level of probability of the loss event or the size of the loss involved* instead of increasing the *certainty* of a loss. First-hand smoking, which is generally acknowledged to “cause” cancer, merely increases the probability of cancers (and other ailments) manyfold. Accordingly, smokers have a higher *expected prospective cost* for life and health insurers than do nonsmokers, even though it cannot be foretold with certainty whether any particular individual smoker will get a specific ailment during his or her lifetime. Insurers can justify charging higher premiums to smokers on the basis of these higher expected loss costs. In fact, upon further examination, it is apparent that *all* the variables used in insurance classification are related only *empirically* to the losses and are hence statistical (as opposed to causal) in nature.

Moreover, the determination of “causality” of most variables used for insurance purposes is not even possible within the social and legal structure of the U.S. In fact, the contemplation of the enforcement of a strict statistical experimental design sufficient to “prove” causality of most insurance rating factors such as sex, marital status, and healthy lifestyle with random assignment and enforcement of individuals into different “treatment cells” is so repugnant to our societal values that the standard cannot be seriously considered. All we allow is the use of variables that are *statistically* related to a loss variable. Those variables are used that do have a high degree of explanatory power for predicting future expected losses and can be obtained at a relatively low cost. Genetic variables have at least as clear a “causal” link to prospective losses as do other variables used in health insurance (even if we do not understand the exact method by which the variables work to produce the loss). It remains to be seen whether or not the gathering of such information is sufficiently cost effective that it saves more information in prospective loss costs than it costs to perform the tests themselves.

The Credibility of the Data

The ultimate criterion by which a classification factor must be judged is empirical. For an empirical test, the credibility of the data used to determine the classification factor’s relationship to ultimate losses is

crucial. This is a legitimate regulatory (and legislative) concern for determination of the appropriateness of a classification variable. The ambiguities of genetic testing must be understood to address which tests could or should be used to underwrite individuals. In a competitive market, however, companies who expend the resources to gather and analyze irrelevant or only marginally important information (or information that their consumers feel is invasive) will face decreasing returns and market penalties. Alternatively, personal attributes, which *are* relevant, are worthy of consideration for inclusion in a classification plan strictly on a cost-benefit basis.¹⁶ In fact, as noted in the previous discussion, the issue of data credibility associated with insurance risk-based pricing can be resolved in a competitive market in which all insurers strive to determine the optimal classification system by trial and error and develop experience with the application of the variable in actual classification use, assuming all have access to the same set of information. If an insurer chooses to use a fallacious variable, its use in a classification plan in a competitive market will ultimately lead to adverse economic consequences for the insurer and will be eliminated.

A complication of this concept in the setting of genetic testing/insurance classification is that, at this time, the results of genetic testing are not clear-cut. According to a 1990 U.S. Office of Technology Assessment report, use of genetic tests as they stand today raises ethical and procedural questions about the accuracy of the tests, the interpretation of results, and how the information will be used (Frieden 1991). For example, research shows that genetic mutations can increase the probability that the carrier will develop a specific disease, and the probability that a disease will occur can vary widely.

Types of genetic disorders can be divided into two categories: genetic diseases and genetic predispositions. In genetic diseases, the genetic component is so strong that it will affect the individual, regardless of what the individual tries to do to avoid it. With genetic predisposition, the disorders may or may not occur, depending on several factors (Pokorski 1992).

For instance, while a woman with a mutated BRCA1 gene has an 85% chance of developing breast cancer,

¹⁶The insurance market is quite competitive. For example, in 1992 there were 3,875 property-casualty insurance companies and some 6,000 life-annuity companies registered to do business in the U.S., any one of which can fairly easily enter or leave the marketplace. Moreover, traditional economic measures of “competitiveness” such as the Herfindel Index also support this conclusion of competition (cf., Witt, Brockett, and Aird 1993).

the age of onset or the tissues that will be affected cannot be predicted. Moreover, only about 5% of women who develop breast cancer have such a mutation (Dutton 1996). For many other cancers, more than one mutation typically is present before malignancies form. Fewer than 10% of common cancers occur in individuals whose family histories put them at risk (Dutton 1996).

If ultimately illnesses and predisposition are *defined* by genetic information rather than manifest clinical symptoms and signs, then the class of sufferers termed the “asymptomatic ill” will grow. These people’s illness only resides in their DNA sequences; it may never become a functional disease (Billings 1993). Most of the state laws allow insurance companies to take the information into account “if there is actuarial or claims experience” to justify its use. Unlike the 1995 California law, they do not address the concept of predictive medicine, which forecasts an individual’s likelihood to contract an illness (Shulman 1995).

Premiums Should Be Individually Determined

A final criticism sometimes leveled against the use of classification techniques is the complaint that individuals should have their premiums determined solely on the basis of their own particular individual characteristics (such as their individual driving record) and not on the basis of their membership in some abstractly defined group that includes individuals with similar characteristics such as age, marital status, sex, territory, or type of car. In fact, this criticism contradicts the entire concept of insurance risk transfer as discussed earlier. The insurance mechanism is *designed* to substitute average group expectancies for individual-realized losses. The process of classification is *intended* to group together individuals who are expected to experience similar loss costs and to distinguish among heterogeneous groups for pricing purposes. This is a reasonable and rational economic objective in a competitive market. For genetic information, the risk pools may change, but pooling is still necessary for the insurance mechanism to work.

EMPLOYMENT ISSUES

The availability of insurance and the tie between employer-based group health insurance, self-insured employer worker’s compensation plans, and employment show that the genetic testing/insurance issue is also an employment issue in the U.S. Group health insurance now makes up 85% of all health coverage,

and most group health plans do not require any “evidence of insurability” from individual members (Shulman 1995). If the insurance company is given information about a genetic test, does the employer that is paying the premium for the employee have a right to access this information? Because genetic discrimination was specifically excluded from the Americans with Disabilities Act, a number of state and federal bills were quickly introduced that would prohibit using the results of genetic testing (“Genetic Testing,” 1992). In March 1992, when Wisconsin passed the first genetic testing law in the U.S., it dealt with the employment issues of genetic testing.

Many companies have foregone traditional insurance and have chosen to self-insure. While self-insured companies may be exempt from state laws as they relate to health benefits, all employers are governed by the Americans with Disabilities Act (Dutton 1996). Therefore, employees of these companies may be vulnerable to medical privacy issues. In these cases, the principal federal antidiscrimination legislation that is potentially applicable to the issues raised by genetic screening are Title VII of the Civil Rights Act, the Employee Retirement Income Security Act, and possibly an expanded interpretation of the 1990 Americans with Disabilities Act. Employers acknowledge that a “vast uncharted legal territory exists where employers’ other responsibilities” clash with an employee’s need for privacy (Wise 1995). These clashes occur primarily in the areas of hiring, wellness incentives, and employee assistance programs (Wise 1995). Often human resources departments are caught in the crossfire between serving the employer and protecting employee privacy because they are charged with developing policies and dealing with labor issues. Therefore, human resources are searching for solutions to satisfy both priorities (Greengard 1996).

Questions about the Reliability of Genetic Tests

Another question to be answered is whether genetic tests are a valid measure of future losses. According to Nelkin and Tancredi (1989), interpretations of diagnostic test results are generally based on the following three assumptions:

1. Technology is sensitive to the pressure of a biological condition allegedly existing in the tissue under examination.
2. The test is specific, that is, able to distinguish meaningful from relevant conditions. The marker

of abnormality revealed by the test must be consistent with the actual behavior or pathological condition experienced by those who have an alleged disease.

3. The test is valid. It is a more legitimate sign of disease than self-reported symptoms and can be used to anticipate the presence of disease in the absence of overt manifestations.

Using the preceding assumptions, genetic tests reveal markers for disease: "The markers are assumed to project a meaningful and valid description of a biological condition that can be used to predict disease. The markers, however, are only signs of aberration— independent of any behavioral or physical dysfunction" (Nelkin and Tancredi 1989). The results of the exams are viewed as a more objective measure of future disease than other available information such as actual symptoms.

Although genetic tests give "signs" of present or future disease, genetic causation makes interpretation of these "signs" very difficult. For example, characteristics such as height, weight, intelligence, personality, and longevity are usually recognized as the product of genetics and environment; however, such characteristics are not factored in after the disease is discovered to be "genetic." This tendency is based on projections from disorders such as Huntington's disease or cystic fibrosis, in which the presence of the gene is diagnostic. These single-gene defects have become the precedent by which to diagnose. However, applying the same type of analysis to conditions such as obesity, alcoholism, or common disorders such as heart disease would be overlooking the complexity of such disorders. When analyzing these disorders, one must not confuse the presence of a genetic or biological condition with the actual disease, since most genetic disorders are the product of the interaction of several genes with a person's environment. One must also realize that any given gene may be responsible for several traits. Even if a test can detect with complete reliability a gene, a cluster of genes, or an extra chromosome, it will not necessarily provide information about the timing or severity of a disability or how it might affect the normal functioning of the afflicted individual (Nelkin and Tancredi 1989).

The fact that many diseases can be controlled through environmental changes illustrates the point that the presence of a specific gene does not necessarily mean that the person will develop the disease. For example, phenylketonuria (PKU) is a severe inherited genetic disorder in which a person may experience mental retardation if exposed to phenylalanine.

However, if the individual is never exposed to phenylalanine in his or her diet, PKU will never develop. Genetic tests are unable to account for other variables such as diet, lifestyle, and the effect of environmental or social interactions that may influence whether or not a genetic propensity actually results in a manifestation of the disease (Nelkin and Tancredi 1989).

As shown by the previous examples, medical researchers have chosen to focus on a single variable in complex disease etiology and thus minimize the possible role of other parameters. This analysis increases the potential for diagnostic fallacies in tests that rely on inferential evidence, as assumptions that are statistically grounded may have little relevance to an individual case. For example, the very presence of a marker or brain abnormality may be defined as disease when no clinical manifestations exist. Once a test is found to identify a marker for a disease, all of those with the marker are classified in the same way by clinicians. In time, routine use could obscure the uncertainties inherent in tests, the underlying assumptions could remain unquestioned, and the marker could become redefined as the disease (Nelkin and Tancredi 1989).

To be reliable, a test must produce a sign of disease that is highly correlated with both the self-reported symptoms and the somatic manifestations of a given condition that are detectable through surgery or autopsy. For example, early studies of the errors in reading X-rays found that misinterpretations stem from such factors as faults in materials, inadequate knowledge of the normal structural variance in the body, and the personal career biases of physicians (Reiser 1978). Improved technology and automated systems that rely less on human judgment would create greater accuracy and precision. Psychologists Daniel Kahneman and Amos Tversky found similar results when they studied the systematic character of interpretation bias. They observed that even experts frequently ignore objective information and make important choices based on bias-laden heuristic reasoning (Kahneman and Tversky 1974).

Many researchers for the Human Genome Project believe the optimal goal of their research is widespread genetic screening in which all individuals could be tested for genetic disorders. However, as shown previously, the results of the Bayesian theorem imply that a more realistic use of the results of genetic tests is as a likelihood measure for determining whether or not an individual will develop the disorder. A minimum of six discrete screening scenarios for genetic

testing were specified by Crandall and Moseley (1991). The person screened:

1. Is certain to get X (or "already has it, subclinically")
2. Is at some explicitly specified risk of getting X
3. Is at increased, but unspecified, risk of getting X
4. Will get or is at elevated risk of getting X if medical or preventive measures are not taken
5. Will get or is at elevated risk of getting X if personal lifestyle behavioral changes are not initiated
6. Will get or is at elevated risk of getting X if exposed to some disease vector, for example, chemicals in the workplace, radiation, or infectious agents.

The preceding scenarios acknowledge the presence of various factors in the development of medical disorders, and researchers need to study such factors before genetic screening becomes widespread. While discrimination against an individual who is certain to develop a disorder is one problem, discrimination against an individual who might develop the disorder is an even larger problem. Ignoring the gray areas in genetic testing discredits such research and wrongfully discriminates against individuals in the process. Therefore, public policies must be developed to protect and balance both individual rights and the integrity of social institutions.

PROPOSED APPROACHES TO OBTAINING A SOLUTION

Because of the issues involved and the complexity of this problem, relatively few solutions to the dilemma of genetic testing and insurance underwriting or classification have been proposed. More commonly, only partial solutions have been advocated that have attempted to address only some of the major issues surrounding this dilemma. The solutions that have been offered are considered in turn.

Totally Delay the Decision on the Use of Genetic Testing by Insurers

One of the solutions currently being used in the genetic testing and insurance dilemma is to avoid a decision. In fact, delaying decision-making on this difficult issue is not without merit. Marvin Schwalb, Ph.D., director of the Center for Human and Molecular Genetics at the University of Medicine and Dentistry of New Jersey, argues that the fear of repercussions of genetic testing will be moot within 25 years, because "as predispositions to more common disorders are

genetically identified, everyone will be predisposed to something" (Dutton 1996).

Even if the issue is not resolved in this time frame, delayed decisions on this issue have other benefits. Since the issue is not easily solved, more time and consideration of the issues may produce better solutions. As of April 1996, most states do not have any legislation on genetic testing (Feldbaum 1996).

A major drawback to delaying the decision totally is that a delay does not protect the privacy rights of individuals. All the other issues are not adversely affected by the delay as long as a decision is being formulated and the extra time is being utilized. While a delay in the decision-making process can be a good tactic for the short term, if the issues are not addressed in a reasonable time frame, privacy rights could be violated.

Delay with a Moratorium

Some states have chosen a different strategy for the interim period between the decision to delay and the ultimate decision. Ohio dealt with the genetic testing/insurance issue by passing a law in late 1993 that imposed a 10-year moratorium on the use of genetic testing by health insurers that started in early February 1994 (Crosson 1994). Similarly, the U.K. House of Commons Science and Technology Committee, following the lead of the Netherlands, in 1995 called for a moratorium on insurers using genetic information on policies below a certain value based in large part on evidence given by geneticist and patient interest groups. They chose a \$100,000 face value limit since it was argued that actuarially adverse selection became problematic above this limit. A final decision has been considered by European countries and delayed several times. Currently, this issue is to be decided by government ministers when they vote on the draft European Bioethics Convention in autumn of 1996 ("Vote on Draft Genetic Convention Close," 1996).

This strategy puts a premium on the right to privacy at the expense of insurance company insolvency. In fact, adverse selection is ignored. The issues of variation in testing results, focusing on genetic testing/insurance issues, and employee concerns may or may not be addressed. One problem in delaying decision-making is that a final decision is never reached, as evidenced by the repeated delays noted in Europe. If this strategy is put into action, interim objectives and work items should be part of the plan.

Protect Public Now/Continue Decision-Making Process

Billings (1993) compares the genetic discrimination issue to that of sex and race discrimination. He advocates for public policy and legislation intervention to “protect the vulnerable while a process of education is concurrently undertaken.” He acknowledges that “passing laws in the absence of public understanding and consensus can cause problems and be an ineffective form of social change.”

This strategy is similar to delaying with a moratorium but is more proactive. Therefore, the concerns of the “moratorium with a delay” solutions are magnified. In addition, the central focus shifts to the insurance mechanisms instead of genetic testing.

Legislative Issues Associated with Classification

Some legislation is geared not only to protect privacy but also to prevent consumers from being classified differently by insurance companies because of genetic testing results. Many states have enacted laws that prevent genetic test results from being used to deny access to health insurance, group disability insurance, or long-term-care insurance coverage. By the end of 1994, nine states had laws specifically addressing genetic discrimination for either insurers or employers: Arizona, California, Colorado, Iowa, Ohio, Oregon, Montana, Rhode Island, and Wisconsin (Dutton 1996).

New Jersey passed what is deemed the “toughest standard in the nation on genetic testing” in June 1996. The New Jersey Genetic Privacy Act establishes a framework to protect consumers from unauthorized genetic testing, unauthorized use of genetic information, and discrimination based on test results. For health insurers, the New Jersey bill creates an outright ban on the use of genetic information. Life and disability insurers, however, can administer the tests and use the information to underwrite their policies if there must be a distinct relation between a particular gene and an increased incidence of death or disability. The legislation also specifies that life insurers must notify an applicant if a genetic test is required and get the individual’s written consent before the test is administered. As a part of this bill, the insurance commissioner can penalize companies that don’t comply with the rules (Schmitt 1996).

Similar legislation is being formally considered in New York. In addition, another New York bill—A.B. 8963—specifies that genetic predisposition to disease, as determined by a genetic test, could not be

used by health insurers to deny coverage or set different rates. Also, the test information could not be used as a basis for any preexisting condition exclusion. The bill has passed the General Assembly and is still pending in the Senate. Under the consent bill, a \$1,000 fine can be imposed for testing without prior approval. For revealing, soliciting, or possessing confidential information without authorization, a penalty of \$5,000, imprisonment up to 90 days, or both can be implemented (Schmitt 1996).

The Oregon law that went into effect on September 9, 1996, prohibits discrimination in employment or obtaining insurance based on genetic information. This law defines genetic information as information about an individual or family obtained from a genetic test of a DNA sample. The law requires informed consent as a general rule for testing subjects with some exceptions, plus it establishes that the genetic information resulting from such tests is the property of the individual (“Guidelines for Use of Genetic Testing: Portland, OR,” 1996).

The states that disallowed classification in genetic testing issues have raised privacy rights and employee concerns onto a higher pedestal while invalidating the business concerns of insurance companies. In their efforts to achieve their objective, they have lost sight of the genetic testing and insurance issue and declared war on the insurance industry in this forum. The diversity of genetic testing results is not addressed. In addition, since these are not delay strategies, the issues may not be addressed any further.

Use of a Reinsurance Pool

In 1995, the U.K. House of Commons Science and Technology Committee suggested a method of spreading the cost across the industry. Under this proposal, insurers would not have access to an individual’s genetic information, and the individual’s privacy rights are protected. If a policyholder dies of a condition that is genetically predictable or detectable, however, the insurer would have to pay only up to a pre-set limit, rather than a higher rate payable if full access to genetic information had been available. In this manner, individual insurance company solvency is protected. However, the insurance industry is still held accountable because a reinsurance pool would be established for companies writing life and health business to cover exceptional claims relating to genetically identifiable causes of death (“The Genetic Link,” 1995). Again the lines between social programs and insurance companies are blurred, and the genetic testing issue is transformed into an argument against insurance.

State Subsidies

Ross's (1995) solution addresses the issue that insurance companies are often asked to subsidize social programs. He suggests that "if state legislatures feel that high-risk people should be entitled to low-cost insurance, let them subsidize it rather than trying to force the insurance industry and the healthier part of the population to do the subsidizing." This proposition illustrates a lack of distinction between the insurance business and social programs yet urges the public to take responsibility. Privacy rights are not violated, and insurance company solvency is not threatened. The variation of test results and employee issues become public policy issues that still need to be resolved. Even though the costs of the provision of health care under this solution have been taken away from the insurance industry, these costs have merely been transferred to the taxpayers, who may or may not be willing to pay.

Genetic Insurance

Tabarrok (1994) proposes genetic insurance as a possible solution. He states that solutions such as consent laws are impractical and create adverse selection problems. He proposes that genetic insurance can eliminate these problems and allow everyone to be insured. His solution requires that mandatory insurance be purchased by every individual taking a genetic test. If the test comes back positive, the individual would be paid a large sum of money to cover the expected cost of the disease. Those with negative results would lose their genetic insurance fee but would gain the results of the test and lower health insurance premiums. This solution protects individual privacy and the insurance industry at the same time. In a competitive genetic insurance market, the issue of variation in genetic test results may or may not lead to different sets of premiums for different tests. The insurance mechanism is not attacked but used to resolve the problem. The success of this solution depends on whether the genetic insurance market could remain solvent. Genetic testing is expensive and not generally used without cause. If a high positive test rate leads to high genetic insurance policy losses, this alternative may not remain viable.

Approved List of Allowable Genetic Differences

Walter Bodmer of the Imperial Cancer Research Fund believes that legislation should be passed to control the use of tests by employers and insurance companies

and that there should be an approved list of the genetic differences that an employer is entitled to know about. In all other cases, employees should not have to reveal genetic information to their employer (Thatcher 1996). If the approved list concept that Bodmer suggests is applied to insurance companies, this may be a solution for balancing the two major issues: an individual's right to privacy and insurance company solvency. Unlike all the other proposed solutions reviewed, the variation of genetic test results would be directly addressed. Bodmer's solution has already balanced employee and employer issues. The insurance mechanism would be restricted but not eliminated and turned into a social program. The process used to create the "approved list" would need to be determined carefully. If this issue can be successfully addressed, the approved list solution has potential.

Increased Data Option on Insurance Policies

In the option for increased data on insurance policies, the insured would be given the right to choose the level of medical and genetic information that he or she would give to the insurer. In exchange for the right to withhold this additional data from the insurance company, the insured would be placed in a higher-risk pool by the insurance company. The insured would have the following choices:

- Choice 1: Not take genetic tests
Result: Increased risk premium
- Choice 2: Take genetic tests, not disclose information to the insurance company
Result: Increased risk premium
- Choice 3: Take genetic tests, disclose genetic testing information
Result: Actuarially fair premium charged by the insurance company.

In this solution, people who choose not to take the genetic tests and people who are not predisposed to diseases yet want to keep their genetic information private are subsidizing those who are predisposed to diseases but are not disclosing the information. The rationale for this cross-subsidization is that these people have gained the option of keeping their genetic information private.

In addition, the risk premium for individuals who select choices 1 and 2 would be spread among a large group of insureds because the cost of genetic testing is not conducive to widespread testing, so most of the insureds would fall into this group. This contrasts with

the Tabarrok concept of mandatory genetic insurance, in which only a small pool almost exclusively composed of higher-risk individuals would lead to a very high or prohibitive price of premiums.

As the lines between genetic testing and other forms of medical diagnosis become blurred, the increased data option could be easily modified to several different levels. The minimal level would be the traditional information supplied to insurance companies. There could be one or more levels of differing amounts of disclosure, yet the concept of exchanging the right to privacy for an increase in premium would remain constant. The introduction of more levels would give a varying degree of increase in premium for corresponding protection of privacy.

Since genetic testing is not currently being used by insurance companies, this solution is not necessary at this time. However, this solution can be discussed and improved upon and could become a viable option for the future.

CONCLUSIONS

In a recent speech, George Poste summed up the genetic testing/insurance controversy when he said, "Solutions must be agreed upon with the full recognition that there are no absolutes, no complete solutions and that background briefings for politicians to confer the wisdom to address issues of this complexity are not easily crafted" (Poste 1995). As Martin Luther King, Jr. said, "All progress is precarious, and the solution of one problem brings us face to face with another problem."

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