POLICY FORUM: HUMAN GENETICS

A Rational View of Insurance and Genetic Discrimination

William Nowlan

Since its inception in 1990, the Human Genome Project has committed 3 to 5% of its annual budget to study the ethical, legal, and social implications (ELSI) of genomic information (*1*). However, in the ELSI program's effort to seek specific solutions to potential problems, the distinction between science and advocacy has been lost.

This problem became apparent to me as the medical director of a life insurance company. While struggling with the question of how life insurers might ethically respond to the challenge of advances in predictive genetic testing (*2*, *3*), I have been troubled by the extent to which the larger debate has been shaped by unsubstantiated fears and misconceptions.

Health insurance and the rush to judgment. The Human Genome Project was conceived and funded to improve human health. It is understandable and admirable that individuals involved are determined to see that it is not misused. People find it unthinkable, for example, that an insurer should use an unfavorable genetic test result to deny or limit access to health insurance and thus to health care. Most states have enacted laws that prohibit use of such information in underwriting medical insurance. Although current federal law (under the Health Insurance Portability and Accountability Act of 1996) prohibits use of predictive genetic information only in the determination of eligibility for group health plans, the Genetic Nondiscrimination in Health Insurance and Employment Act under consideration in Congress would extend this prohibition to all health insurance programs. Such laws may serve a useful symbolic purpose, but the rationale for their enactment is flawed—the erroneous belief that the threat of genetic discrimination by health insurers represents a clear and present danger.

The assertion that genetic discrimination in health insurance is a real problem pervades the ELSI literature (*4*–*6*) but evidence has been almost entirely anecdotal. In 1998, Hall and Rich (*7*) surveyed medical geneticists, genetic counselors, regulators, actuaries, insurance underwriters, and insurance agents in seven states to determine whether existing laws have been effective in reducing genetic discrimination. Market tests were also conducted in which health insurance coverage was sought for fictitious individuals with an unfavorable family history or a problematic genetic test result. The surprising conclusion was that these laws have no measurable impact because they address a problem that does not seem to exist. The investigators attribute this finding in large part to the fact that most individual health policies remain in force only a few years, and insurers have little economic incentive to underwrite based on a theoretical risk of future disease.

At the 1999 meeting of the American Society of Human Genetics, a panel of lawyers, genetic counselors, and geneticists reported that they had been unable to identify any cases of discrimination by health insurers. A report of the session likened fears of genetic discrimination by health insurers to "urban legends that are built on rumor rather than fact" (*8*). However, articles continue to speak of such discrimination as a current menace (*6*). Responsible discussion needs to acknowledge the compelling evidence that at present the threat seems to be largely theoretical.

The meaning of life insurance. Life insurers have so far been largely successful at arguing against restrictive legislation. Although some attribute this to the political power of the life insurance lobby, it more likely results from an ability to convince legislators that a clear distinction exists between economic and ethical considerations involved in underwriting health insurance and those that apply to life insurance.

Life insurance in this country is not a societal right, although everyone is potentially eligible for limited survivorship benefits through social security. The private insurance system provides a financial safety net, but it is voluntary and unsubsidized. An individual life insurance policy is, in effect, a commercial transaction in which the insurer agrees to pay a death benefit in exchange for a premium proportional to the mortality risk assumed by the insurer. If this seems to resemble a grim lottery, its only "winners" are those who are acutely in need.

Coverage is offered to 95% of Americans who apply for individual life insurance policies; about 90% of these policies are issued at standard or preferred rates (*9*). Life insurance is affordable simply because, for most people, the risk of premature death is small. Although critics believe it is fundamentally unjust that the lowest rates are not available to all, is it more "fair" to require low-risk individuals to make what is in effect an involuntary and non–tax-deductible donation to help fund death benefits of others at higher risk? As long as purchasing life insurance is a matter of personal choice, fairness dictates that insurers classify risk properly and charge accordingly.

Accurate risk classification requires that insurers verify medical information. However, this process increasingly conflicts with a public desire for medical privacy. Considerations of fairness aside, there is a growing body of economic theory that suggests that such "information asymmetry" can seriously disrupt the efficient functioning of a free marketplace. The 2001 Nobel Prize in economics was awarded for work in this area, and the citation specifically references how private information may lead to adverse effects in insurance markets (*10*).

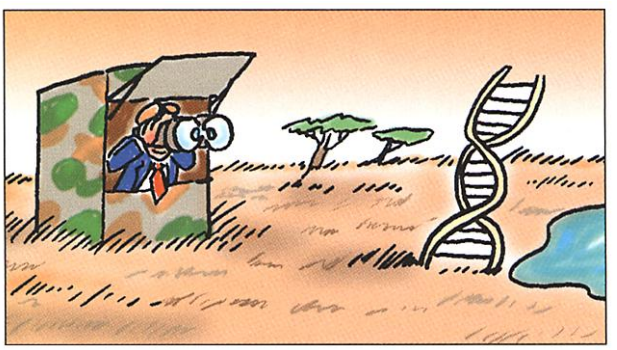
The threat of genetic discrimination by life insurers. Even if society can accept the need for a life insurer to charge a higher premium based on life expectancy, ethical considerations in pricing genetic risk are more complex and troubling because the risk of disease is present at conception and is often inescapable. It also might seem reasonable to worry that genetic risk will be of greater interest to life insurers than health insurers, because a policy will often stay in force over many decades. But, except for the gene associated with Huntington's disease, genetic risk in an otherwise healthy adult does not preclude affordable coverage. Furthermore, the mutation is rare, occurring in about 1 in 20,000 people. The impact on insurance risk classification of genetic testing for predisposition to more common, multifactorial diseases would be much less.

In 1994 and 1995, the *BRCA1* and *BRCA2* genes were described. Mutations of these genes might occur in as many as 1% of certain populations and confer a high lifetime risk of developing breast and ovarian cancer. Many believed that these genes represented the vanguard of a new class of tests for predisposition to common diseases. But despite an intensive search, other similar "blockbuster" genes have not been found, and it appears that on average the excess mortality risk associated with carrying either a *BRCA1* or *BRCA2* mutation might be comparable to the risk of smoking cigarettes (*11*).

The author is with the National Life Insurance Company, Montpelier, VT 05604, USA. E-mail: wnowlan@nationallife.com

Massachusetts recently enacted a genetic testing law (*12*) that provides a regulatory framework for how life insurers may consider existing genetic test results in underwriting. After satisfying a two-step consent requirement, the insurer may consider test results if they are deemed "reliable," a determination that may ultimately be made by the insurance commissioner. I believe such regulation is unnecessary as long as the free market is unlikely to operate capriciously or to create a "genetic underclass."

Last fall, the Association of British Insurers, under threat of restrictive legislation, agreed to a 5-year moratorium on the use of genetic test results in underwriting life insurance policies under £500,000. I fear that this approach only tends to reinforce the perception that insurers are eager to engage in genetic discrimination. It represents a "solution" based on an untested hypothesis and impedes our ability to implement sound policy based on actual experience.



Even symbolic laws can impose a cost if they are targeted inaccurately (*13*). In 2002, it is certainly arguable that life insurers could absorb the additional mortality costs resulting from "genetic privacy" legislation, but such legislation would become increasingly unworkable over the course of a continuing genetics revolution. Any effort to selectively blind life insurers to the results of genetic tests already in the clinical record will prove to be highly problematic. Individuals who advocate restrictive legislation must be able to identify the societal ill that warrants requiring insurers to operate in a regulatory minefield where any adverse underwriting decision may be attributed to consideration of routinely gathered (but protected) information.

A separate issue is whether life insurers should be allowed to order genetic tests. A genetic testing bill (*14*) enacted in Vermont in 1998 implicitly allows life insurers to consider existing genetic test results, but prohibits them from ordering new tests to screen applicants for genetic risk of future disease. I believe that such a law has merit. Information asymmetry is not an issue if testing has not already been performed. Still, it is hard to imagine how insurance companies could profit from insurer-initiated genetic screening. The reality is that competitive pressure to increase sales already prompts most companies to accept, rather than avoid, marginal risks. It is increasingly likely (*15*, *16*) that the power of genetic testing to predict mortality in otherwise healthy adults will never be compelling enough to justify the expense of testing or the inevitable public furor.

Conclusion. Opinion expressed for the purpose of influencing the actions of individuals or groups is propaganda (*17*), not science. I concur with Greely: Those who are tempted to build support for regulation by exaggerating the importance of the problem do so "at a cost to accurate public understanding of the real significance of genetic variation and human genetics research" (*18*). Society is best served when discussion of ethical and social issues relating to science is conducted in the same rational and unbiased manner as the science itself.

References and Notes

1. www.nhgri.nih.gov/ELSI/aboutels.html#When
2. W. J. Nowlan, *On Risk* **15**, 39 (1999); available by request.
3. _____, *National Underwriter* (31 January), 19 (2000).
4. E. V. Lapham *et al.*, *Science* **274**, 621 (1996).
5. K. L. Hudson *et al.*, *Science* **270**, 391 (1995).
6. G. J. Annas, *N. Engl. J. Med.* **345**, 385 (2001).
7. M. A. Hall *et al.*, *Am. J. Hum. Genet.* **66**, 293 (2000).
8. J. Stephenson, *JAMA* **282**, 2197 (1999).
9. *Life Insurers Fact Book 2000* (American Council of Life Insurers, Washington, DC, 2000).
10. www.nobel.se/economics/laureates/2001/press.html
11. M. Engman, presentation at the American Academy of Insurance Medicine Annual Meeting, San Francisco, 21 October 1998.
12. *Mass. Gen. L.* chap. 254 (2000).
13. M. A. Hall, *New York Times*, 19 February 2000, p. D7.
14. Acts of the 1997–1998 Vermont Legislature, no. 160.
15. N. A. Holtzman, T. M. Marteau, *N. Engl. J. Med.* **343**, 141 (2000).
16. H. G. Welch, W. Burke, *JAMA* **280**, 1525 (1998).
17. A. M. Lee, E. B. Lee, *The Fine Art of Propaganda* (Harcourt Brace, New York, 1939); see http://carmen.artsci.washington.edu/propaganda/home.htm.

→ H. T. Greely, *Univ. Penn. L. Rev.* **149**, 1483 (2001).

POLICY FORUM: HUMAN GENETICS

Before It's Too Late—Addressing Fear of Genetic Information

Karen H. Rothenberg* and Sharon F. Terry

The application of genetics to human health is poised for dramatic expansion. The draft sequencing of the human genome has already led to discoveries about some of the genetic factors contributing to heart disease, diabetes, Parkinson's disease, asthma, and other common illnesses. Before 2010, people may be able to learn their genetic susceptibilities to common disorders, allowing for design of individualized preventive medicine through life-style changes, diet, and medical surveillance (*1*). We may be able to predict who will respond effectively to a particular drug therapy and who will suffer side effects.

Public support for the Human Genome Project is based on its promise for improving human health (*2*). However, this enthusiasm has been tempered by fear that information about our genetic make-up will make us vulnerable to discrimination by insurance companies and employers. Such fear, whether justified or not, has already had negative effects. A recent study reported that about one-third of people expressed concern that genetic testing could cause them to lose their health insurance, and these apprehensions caused some not to participate in clinical research protocols (*3*). Another study found that fear about health insurance discrimination was the most frequent reason for declining genetic counseling services (*4*). Furthermore, surveys reflect the public's distrust. In July 2000, *Time* magazine reported that 75% of those surveyed would not want their insurers to know what diseases they are predisposed to (*5*). Another study found that 68% of people surveyed would not bill genetic testing to their insurance company, and 26% would use an alias to reduce the risk of insurance discrimination (*6*). Clearly, there are many reasons why individuals might choose not to utilize genetic services, but fear of discrimination should

K. H. Rothenberg is dean and Marjorie Cook Professor of Law, University of Maryland School of Law, Baltimore, MD 21201, USA. S. F. Terry is president, Genetic Alliance, Washington, DC 20008, USA.

*To whom correspondence should be addressed. E-mail: krothenberg@law.umaryland.edu

CREDIT: JOE SUTLIFF