

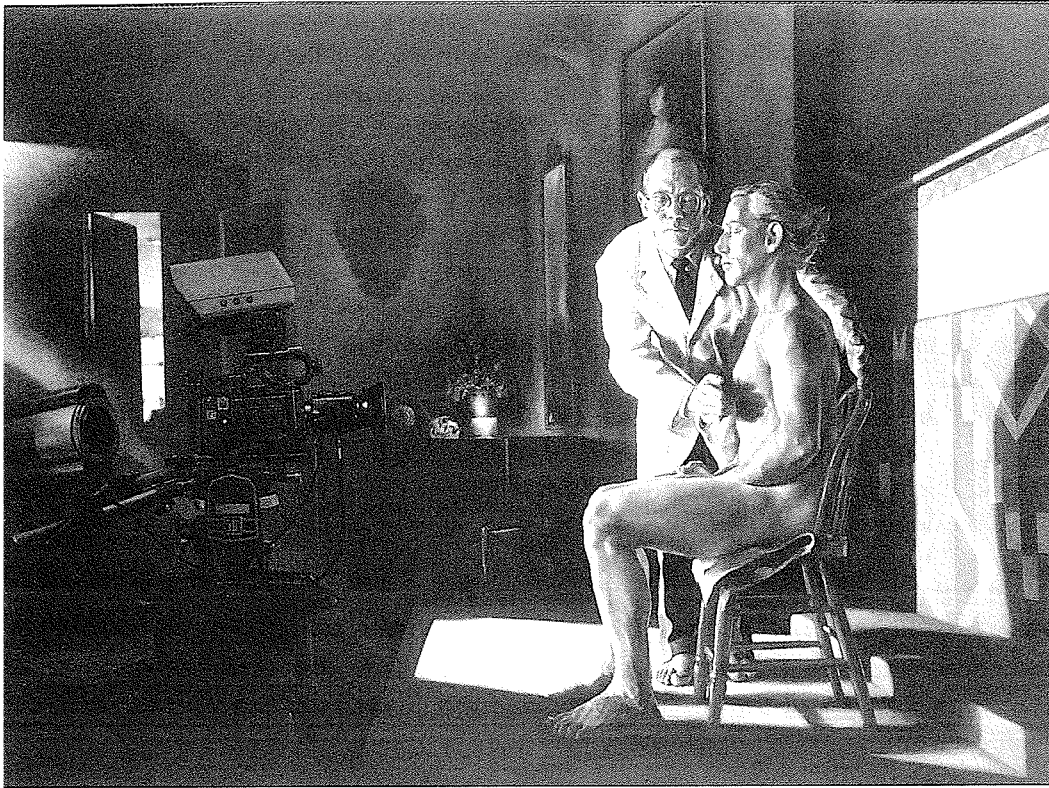
The Genetic Surprise

by Phillip J. Longman and Shannon Brownlee

So strong is the American aversion to “socialized medicine” that neither major candidate in this year’s presidential election has dared question the fundamental role of the private sector in underwriting the U.S. health care system. Indeed, most health care reform proposals on the table involve attempts to make private health care insurance more widely available through the use of various subsidies and other incentives. Yet the collision of two well-established trends in medicine and law may soon make the private sector’s role in spreading the risk of health care costs unworkable, and government provision of universal health care coverage increasingly difficult to avoid.

The first of these trends is the rapid advancement of genetic testing and other means of determining proclivity to disease. Ten years ago there were fewer than a dozen genetic tests available, mostly for relatively rare inherited disorders such as retinoblastoma, a cancer of the eye, and cystic fibrosis. Today, tests have come on line for approximately 400 genetic disorders, including common diseases such as Alzheimer’s and cancer, and many more are in the offing. For example, one supplier of genetic tests, Myriad Genetics, a biotech company in Utah, markets a test for a gene that governs which drug is most likely to help a patient with high blood pressure. Within a year, the company hopes to launch tests for genes that contribute to melanoma, an inherited form of colon cancer, and perhaps 20 percent of heart attacks. Within three years, the company hopes to offer tests that predict the risk of asthma, insulin-dependent diabetes, obesity, and osteoporosis.

Other companies are racing to develop tests for the genes that contribute to a rogues’ gallery of diseases such as Parkinson’s, multiple sclerosis, lung cancer, and depression. With the completion of the map of the human genome last July, geneticists expect that hundreds more genetic tests will soon be available. Moreover, the tests are likely to be cheap and easy to administer. Your doctor will scrape a few cells from the inside of your cheek, place them in a device on a tabletop, and look into your medical future. New gene-chip technology, which marries DNA sequencing with the silicon chip inside computers, promises not only to speed the search for additional genes but to bring down the average cost of genetic tests



The Faith Healer (diptych, panel one, 1998), by Geoff Laurence

from several hundred dollars to just a few. Eventually, discovering your genetic destiny, or at least your genetically probable fate, may become as simple and easy as checking your cholesterol.

The second trend that will have an impact on private health insurance is the plethora of “right to privacy” laws passed in response to widespread fears that genetic tests will be used as a basis for discrimination. So far, 37 states have passed legislation that tries, in one way or another, to limit an insurer’s access to genetic information, and there are approximately 200 similar bills pending in various state legislatures. In February, President Bill Clinton issued an executive order that forbids federal agencies from using genetic testing in any decision to hire, promote, or dismiss workers. Clinton also endorsed congressional legislation sponsored by Senator Tom Daschle (D-S.D.) and Representative Louise M. Slaughter (D-N.Y.) that would make it illegal for employers to discriminate on the basis of genetic testing. A similar bill introduced by Representative Slaughter had more than 200 bipartisan supporters in the House and was endorsed by 100 public-interest groups representing a broad swath of the American public.

The political appeal of such bans can hardly be overstated. Many studies have shown that fear of discrimination discourages individuals from undergoing genetic tests that could be useful in prolonging their lives. Genetic counselors report, for instance, that many women at risk for an

inherited form of breast cancer are reluctant to get tested for fear they will lose their insurance. At the same time, discrimination on the basis of genetic endowment violates most people's fundamental sense of fairness. As Carroll Campbell, president and CEO of the American Council of Life Insurance (ACLI), told an industry meeting two years ago: "Our Achilles' heel is that we haven't been able to successfully explain why it's fair to penalize applicants for risk factors they can't control." In fact, Campbell confided that, according to internal polling by the ACLI, fully 80 percent of life insurance industry employees (not including actuaries and underwriters) oppose the use of genetic testing by insurers.

The fact that many genetic markers for disease are strongly associated with specific ethnic groups adds to the potential controversy. Jews of eastern European origin, for example, are far more prone to several harmful genetic mutations than the general population. They face a three- to four-fold increased risk for three mutations associated with breast cancer and approximately a six-fold increase in risk for colon cancer. African Americans are more likely to suffer from hypertension, coronary artery disease, and sickle cell anemia, a disease that almost never strikes northern Europeans or Asians. Caucasian children, meanwhile, face at least a 10-fold increased risk of cystic fibrosis compared with nonwhites.

Yet the ever-tightening legal prohibitions against genetic discrimination create perverse side effects when combined with the trend toward cheap and effective genetic testing. Specifically, the ability of people to keep the results of genetic tests secret causes an asymmetry of information between insurers and insurees that threatens to unravel the very logic of private health insurance markets and, by extension, the viability of the U.S. health care system as a whole.

This mighty threat arises chiefly from a phenomenon known to actuaries as "adverse selection." People who know, for whatever reason, that they face an increased risk of disease or premature death tend to load up on insurance. This presents no threat to the sustainability of insurance markets so long as insurers have access to the same information and can use it to adjust the premiums offered such people to a level commensurate with the risks they present. But when insurers are denied meaningful information about the risks they are underwriting, or are forbidden from practicing price discrimination based on different probabilities of risk, then adverse selection sets in motion a process that at best makes insurance markets highly inefficient, and at worst dysfunctional.

To see why, consider the following thought experiment, inspired by an

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example from David Holland, president and CEO of Munich American Reassurance Company of Atlanta. For simplicity's sake, imagine not a health insurance company, but a life insurance company, called PetLife, which has three types of customers: 1,000 dogs, 1,000 cats, and 1,000 mice. Each customer holds a policy that will pay \$1 in the event of death, but life expectancies vary widely. The cats, blessed with nine lives, enjoy the lowest mortality rates. Only 10 percent of all cat customers die each year. Dogs, prone to chasing cats into the street, suffer a higher mortality rate, with 20 percent dying annually. Finally, there are the poor mice, who, largely because of the cats, have the shortest life expectancy. In any given year, fully 36 percent of mice customers expire.

Obviously, the mice pose the highest risks and the highest costs for PetLife. Indeed, since they are more than three and a half times more likely to die in any given year than cats, many mice find that they can only obtain life insurance at rates that are very high, at least compared with the rates quoted to cats. Sensing an injustice (after all, they had no choice about being born mice), the mice band together as a special-interest group and push a law through Congress that prohibits discrimination on the basis of genetic endowment. From now on, all life insurers will have to offer policies to cats, dogs, and mice at the same price.

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How will insurance markets respond to this mandate? Given the different mortality rates for its 3,000 customers, PetLife can expect 100 cats, 200 dogs, and 360 mice to die by the end of the first year, for a total of 660 claims. Ignoring the cost of overhead and any need for profits, PetLife will need to collect premiums of \$660 to cover each of the \$1 death benefits it can expect to owe each year. Since it is prohibited from practicing genetic discrimination, it must select a single premium price that covers its expenses. After dividing the total amount of expected claims (\$660) by the total number of customers (3,000), the company will discover that the premium it must charge for each policy is 22 cents.

But there is a problem with these single-price policies, especially if you are a cat. With their comparatively long life expectancy, the cats collectively will pay some 45 percent more in premiums than they will collect in benefits. By contrast, the short-lived mice will collect some 61 percent more benefits than they pay in premiums. What would you do if you were a cat? Obviously, you'd be inclined either to look for a new plan with more cats and fewer mice, or perhaps go without life insurance altogether.

And what would you do if you were a mouse? With the company pay-

ing the average mouse \$1 in benefits for every 22 cents it contributes in premiums, PetLife policies are highly popular among mice. It is such a good deal that, unlike cats, few mice ever let their policies lapse. Consequently, over time PetLife's risk pool comprises an ever larger share of high-cost mice, and an ever smaller share of low-cost cats.

As this happens, PetLife will have no choice but to keep raising its premiums to cover the increasing average death rate of its remaining (mostly mice) customers. And each time it does so, its remaining cat customers will face a worse deal, causing still more to flee and requiring a new round of premium increases. Eventually, either PetLife will go broke or the mice will again find themselves paying very high premiums,

with many of them perhaps priced out of the market.

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The moral of the story is that for all insurance markets, not just life insurance, a failure to practice price discrimination against different classes of risks can lead quickly to market failure. This isn't just a matter of theory. In the 19th century, adverse selection created by an antiquated system of one-price-for-all underwriting

made life insurance extremely attractive to the old and sick, and too expensive for the young and healthy. As insurers' costs rose, so did prices, until the product was so expensive only the affluent could afford it.

Something similar is happening today in New York State, where health insurers have been forced by law to charge everyone the same price, based on the average cost of insuring people in each of nine regions across the state. The 1992 community rating law applied not only to insurance for individuals but to rates offered to small businesses. Health insurers had to stop offering better rates to small businesses with young (and therefore generally healthier) workers and charging higher premiums to those with older, sicker workers. The legislation was aimed at bringing prices down so more businesses and individuals could afford health insurance. "What happened was just the opposite," says Mark Litow, an actuary with Milliman & Robertson, an employee benefits consulting firm. Instead, says Litow, "It raised average prices and wiped out the individual market in New York State." Within the first 18 months after passage of the bill, an estimated 365,000 New Yorkers lost or dropped their health insurance. Most of them were young, a pattern that caused prices to rise even more.

Though most Americans receive their health care through group policies in which adverse selection is less of a concern, even group plans are affected by the phenomenon, say industry experts. Individuals who know

they are at elevated risk for genetic disease will seek out employers offering gold-plated health insurance plans (the government, for instance), or will choose to stay with an employer whose health plan is more likely to cover them. Employees with genetic conditions who can pick and choose among different health insurance options will select the plan that best covers the treatment they need.

It isn't just fear of adverse selection that creates a strong incentive for insurers to use genetic information in setting prices. Potentially, price discrimination based on the results of genetic testing could make insurance markets much more efficient, and the price of health and life coverage much lower for most people, albeit much higher for more than a few. It is a well-established principle of economics that when consumers have vastly different demand curves for a product, charging higher prices to those who need the product intensely, and lower prices to those who want it only weakly, often leads to lower average prices.

An example is the airline industry, which fills seats that would otherwise go empty by offering steep discounts to people who have no urgent need to travel and can purchase tickets far in advance. The presence of such people makes the average cost of tickets lower than it otherwise would be, because the cost of the flight is spread among more passengers. The public benefits that can accrue from price discrimination against different classes of customers were widely recognized as far back as the late-19th century, when government regulation of railroad freight and passenger fares embraced the principle.

The same tenet applies to the use of genetic tests in pricing insurance, and more broadly than one might suppose. Those who know they are blessed with few deleterious genes will have lower demand for health care insurance than those who know they are not, all else being equal. If the genetically fit are charged the same premiums as the genetically unfit, the former will consider health insurance overpriced, and many will simply choose to go bare. The only way to tempt them into a risk pool is to offer them discounts commensurate with the lower risks they present, or, to put it another way, to charge the genetically unfit more.

The use of genetic tests potentially increases the efficiency of insurance markets for another important reason: In effect, it reduces the amount of unknown risk, or uncertainty, insurers must absorb, and thereby allows them to charge lower average prices. Just having additional genetic information about the pool as a whole reduces uncertainty about future claims, notes James Hickman, dean emeritus of the School of Business at the University of Wisconsin, Madison, and to that extent reduces the risk premium that must be built into insurance prices. Even if a pool of employees turns out to have a higher-than-average number of workers with potentially expensive gene defects, the reduction of uncertainty achieved by sharing that information with insurers may well be enough to reduce the cost of insuring the pool to

below what it would be were insurers simply left in the dark about the risks involved.

To see this principle at work in another context, consider which would be the more attractive bet for you: (a) You encounter a person on the Internet of unknown sex, age, and health habits who offers you \$100 in return for your promise to pay his or her estate \$1,000 in the event he or she dies next year, or (b) your 55-year-old neighbor, who you know is at least fit enough to mow his own lawn, but whom you also see smoking on his porch from time to time, offers you the same bargain, with the only difference being that the most he will pay you upfront to take the deal is \$75. Perhaps both proposals are bad bargains, but the second should seem more tempting than the first. That is because the attractiveness of a bet increases as its uncertainty decreases, even when comparatively high real risks are involved. This example shows why laws protecting privacy incur such great costs, and why it should be an open question whether the price is always worth paying.

Allowing genetic discrimination in insurance underwriting would be far less revolutionary than it might seem. Starting in the 1980s, blood testing of life insurance applicants became widespread, as did price discrimination based on the results. Today, some insurers have as many as nine classes of preferred rates based on factors such as blood pressure, cholesterol levels, age, sex, and smoking habits. Far from generating political opposition, such price discrimination has become a marketing tool. As John Krinik, editor and publisher of *Underwriter ALERT*, has noted, "Cultural attitudes dealing with financial status (i.e., preferred, gold, and platinum credit cards, club memberships, etc.) made life insurance marketers believe that competitive advantage would accrue to the insurer who played to these social stratifications."

No insurance company yet offers discounts to the "genetically fit," but many industry observers believe it's only a matter of time before some renegade firm makes the pitch. A sample ad has already appeared in an article on future trends in insurance published in *Contingencies*, a trade magazine for actuaries: "Your genetic profile may qualify for the lowest insurance rate ever offered! You don't have to subsidize anyone else's inferior genes again! DNA Life Insurance Company introduces Immortal Life, the policy for the superior man or woman with unsurpassed gene fitness."

In pondering how health and life insurance markets might evolve if left to their own devices, it is worth noting that many consumers may well want to offer the results of genetic tests to insurance companies. Privacy laws increasingly allow individuals who get unhappy test results to keep that information to themselves. But those who discover they are genetically well-off may want to share that information with insurers in order to obtain lower rates. Similarly, in the future, employers may be tempted to reduce their health care costs by offering the prospect of lower premiums to employees who voluntarily submit to a genetic test.



Many states restrict insurers' access to genetic and other medical information, but individuals can still be required to release such data to their employers.

Lawmakers may try to prohibit such transactions, but arguably this would in itself be a form of genetic discrimination. Why should people who happened to be born without many gene defects (but who may be poor or suffering from nongenetic disease) be forced to pay more for health insurance than is warranted by the actuarial risk their genes are known to present? Alternatively, if those who are prone to genetic disease require a subsidy for their health care needs, why should the burden of paying that subsidy fall exclusively on the genetically fit as a class without regard to their individual health or economic status?

Breast cancer provides a concrete example of how bans on genetic discrimination can cause inequities. About 80 percent of the women who carry BRCA1, a gene associated with breast cancer, will develop the disease. But women with this inherited form of cancer constitute only a fraction of all breast cancer patients. Why should women who carry the BRCA1 gene be a protected class, effectively entitled to insurance priced below the actuarial cost of their benefits, while those who develop breast cancer from other causes are not?

Many people believe that genetic discrimination should be banned

because individuals have no control over the gene defects they inherit. But while the content of our DNA may be a matter of fate, genetic disease usually isn't. Some genetic defects, to be sure, do lead inexorably to disease. For example, people who test positive for the rare gene mutation that causes retinitis pigmentosa know for certain that they will go blind by about age 60. But the results of most genetic tests are expressed in terms of probability. Part of this variability stems from the vagaries of genetics. The same genetic mutation may express itself differently in different people; one identical twin, for example, may develop juvenile diabetes

while the other escapes it. The expression of genes is also affected by lifestyle and environment. If you have a genetic predisposition toward high blood pressure, you may not develop the condition if you exercise and hold down your calories. Many persons carrying the gene associated

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with familial adenomatous polyposis colon cancer can achieve a nearly normal lifespan if they receive regular colonoscopies and have their polyps removed. An inherited predisposition to lung cancer or emphysema can be diminished by giving up cigarettes.

The fact that most genetic tests establish only a predisposition to disease causes some observers to object that such tests should never be used as a basis for discrimination. Doing so, they say, is equivalent to charging blacks higher life insurance premiums just because blacks, on average, have lower life expectancies—actuarially sound, but morally unacceptable. Yet insurance has always been based on probabilities determined through group membership, variously defined. People who have only recently obtained their first driver's license, for example, are often very careful drivers, yet as a class such drivers present enough of an elevated risk of accidents that they are charged dramatically higher premiums than the general population, and without stirring much political objection to the implicit age discrimination either.

Similarly, many, if not most, occasional smokers don't develop lung cancer or other smoking-related illnesses, but enough do so that price discrimination by life insurance companies against all smokers, whether they smoke one cigarette a day or 60, is well established and widely accepted. More significantly, insurers now routinely charge higher prices to people who, while not actually ill, carry mere markers or precursors of disease, such as high cholesterol or high blood pressure. The fact that such conditions often have a genetic component further undermines any attempt to draw moral or legal distinctions between genetic testing and routine medical screening. "The arguments I don't like are the ones that say genetic information is so special that it deserves particular pro-

tection,” says Hank Greely, codirector of the Stanford Program in Genomics, Ethics, and Society. “It’s just another form of predictive information, like sex, age, weight, and past medical history.”

Adding to the pressure on insurers to use genetic information in underwriting is the reality that once one company does it, they all have to, or they run the risk of huge increases in cost. In the early 1980s, for example, when some life insurance companies first charged higher premiums to smokers, insurers that delayed implementing the policy found that the percentage of smokers in their risk pools increased to as much as 60 percent, because smokers sought out the companies that did not practice price discrimination against them.

Yet the insurance industry also faces huge risks of further political backlash if it adopts wholesale genetic testing. This is particularly true when it comes to health insurance, because of the widespread conviction that access to health care is a right of citizenship. “Health insurance carriers are more likely to react in a political fashion than in an actuarial fashion,” says Alex Capron, professor of law and medicine at the University of Southern California. “They are likely not to want to use genetic information even if they could, because they recognize extensive use of it would create a situation of larger numbers of uninsured people, and all that does is feed the demand for health care reform.”

Some observers believe the tradeoffs between equity and efficiency can be reconciled if the government allows for genetic discrimination in underwriting but also creates special benefits or subsidies for people who are thereby left unable to afford insurance. Patrick Brockett, director of the Risk Management and Insurance Program at the University of Texas, advocates a voucher system, similar in method to food stamps, which he believes would be far preferable to an outright ban on genetic discrimination. “We don’t ask supermarkets to sell food at a lower price to disadvantaged people; we give disadvantaged people food stamps,” notes Brockett. “Similarly, we may want to give vouchers to people who, because of genetic tests, can’t afford insurance.” Brockett thinks such a system will start with health care, “because so many people now think it is a right,” and soon spread to types of insurance against human frailty, such as workers’ compensation and life and disability insurance.

Other observers believe that there ought to be a tax on genetic tests that funds a social insurance program for people who flunk them. This would satisfy some people’s sense of justice, to the extent it would require everyone to share the risk of genetic mutations before anyone knew his or her specific genetic liabilities. But others regard such schemes as, at best, half-steps. “That would be the usual American solution,” says Arthur Caplan, director of the Center for Biomedical Ethics at the University of Pennsylvania. “Don’t fix the problem, just enact horrendously costly stopgap measures that bury everyone in red tape.”

In the end, Americans may well decide that the amount of such red

Privacy

tape, combined with the loss of privacy and the genetic discrimination required to preserve private health insurance markets, is just too high a price to pay, and demand the obvious alternative. One virtue of a publicly funded, universal entitlement to health care, which is likely to assume ever greater support as advances in genetic testing continue, is that it instantly solves the problem of adverse selection. Under such a scheme, individuals who are genetically and otherwise fit would still, in a strictly actuarial sense, wind up cross-subsidizing those who are not. But at least the financing of such a system wouldn't be prone to the death spiral that occurs in private insurance markets when cats can walk away and mice pile on.

This is not to suggest that universal health care coverage would be free of problems of its own. Health care, as Senator Daniel Patrick Moynihan (D-N.Y.) has suggested, is a "maximum entitlement." Whether it is provided under a program like Medicare, or by private insurance, health care coverage is essentially an open-ended contract that induces the very events (e.g., visits to doctors) it attempts to insure against. If an underwriter offers you a \$100,000 life insurance policy, there is no ambiguity about what is promised, or how much it will cost in the event of your death. But since few individuals desire their own death, and, in any event, death by suicide invalidates the contract, what actuaries call "moral hazard" (or a situation in which insurance itself makes the insured event more likely to occur) is a comparatively minor issue in life insurance underwriting.

By contrast, when someone offers to pay whatever health care bills you deem necessary to maintain what you consider good health, the obligation is underdefined and totally subject to moral hazard. Because the insured event is something you desire, i.e., medical and mental health care services on demand, the contract or entitlement gives you an incentive to make sure it comes about. Worse, since there is no society-wide agreement on what constitutes good health, or on what medical measures are most effective in achieving it, the cost of your benefits becomes virtually limitless.

Still, what is the alternative? The American health care system is a tangle of contradictions and compromises, reflecting our conflicting tendencies to regard access to health care as a right of citizenship and to rely on market forces as much as possible as a means of pricing and allocating medical services. But these contradictions will become increasingly stark as information about individuals' genetic proclivity to disease becomes more common, accurate, and inexpensive. If genetic information is shielded by privacy laws, adverse selection alone will cause the cost of private health insurance to spiral upward, aggravating the problems of access. If such information isn't shielded, health insurance markets will operate efficiently, but they will also deny a different group of people access. Either way, mitigating such effects will require increased government subsidies or outright socialized medicine. □