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Genetic Privacy

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Executive Summary

There is little, if any, evidence that health insurers are using or likely to use presymptomatic genetic information in their medical underwriting. Evidence that employers try to obtain, let alone use, such information generally is limited to isolated anecdotes. In any event, erecting legal barriers against discrimination based on genetic information would strain the limits of genetic exceptionalism, defy precise definition, pose serious threats to the functioning of private insurance and labor markets, and overlook more effective alternative remedies.

Genetic Privacy

Tom Miller

Good morning, Mr. Chairman and Members of the Subcommittee. My name is Tom Miller. I am director of health policy studies at the Cato Institute. It is a pleasure to appear before you today to examine privacy concerns raised by the possible collection and use of genetic information by employers and insurers.

I say "possible" because there is little, if any, evidence that health insurers are using or likely to use presymptomatic genetic information in their medical underwriting.[1] Evidence that employers try to obtain, let alone use, such information generally is limited to isolated anecdotes. One survey of human resources managers revealed that limited evidence of genetic testing actually reflected misunderstanding of what truly is genetic information, as opposed to routine blood tests or testing for the presence of a disease (rather than a genetic susceptibility to it).[2]

However, this topic usually is built on assumptions about the future and what some observers believe private insurers and employers might do in the event that genetic testing and genetic information eventually became more accurate and precise in revealing an individual's prospects for future disease, incapacity, and unusually high health care claims costs.

As Yogi Berra once said, or probably should have if he did not, "Predicting the future is hard, because it hasn't happened yet." Nevertheless, let's proceed by beginning with what we do know about how private insurance markets and labor markets operate.

It's reasonable to assume that more accurate, comprehensive, and inexpensive genetic testing will arrive one day; the question is more one of the pace at which this will take place. When combined with reliable evidence from epidemiology about the probability and magnitude of various maladies, the continuing genetic revolution promises to improve dramatically our ability to detect disease at an early stage, and treat it more effectively or even prevent it. Better, and earlier, knowledge about genetic

[1] Mark A. Hall. "Legal Rules and Industry Norms: The Impact of Laws Restricting Health Insurers' Use of Genetic Information," 40 *Jurimetrics Journal* 93-122 (Fall 1999).
[2] Eric Greenberg, American Management Association. Testimony before the House Education and the Workforce Subcommittee on Employer-Employee Relations, 107th Cong. 1st Sess., July 24, 2001.

predisposition to illness might help individuals take preventive measures to reduce the consequences of disease or even eliminate its onset. Enhanced use of more predictive genetic information may assist individuals in making lifestyle plans and choices. It also holds great promise in fine-tuning health care treatment, such as through more narrowly targeted "designer" drugs and gene therapy interventions.

But the offsetting concern encompassed in the catchall desire to protect "genetic privacy" is that one's personal genetic information might be disclosed to others without one's consent and then used to one's personal detriment.

Without question, any information that can be used may also be used badly. But a host of policy complications and administrative complexities arise if one attempts to craft a unique brand of legal protection against the disclosure of personally identifiable genetic information in the name of "genetic privacy."

First of all, any possible constitutional protections for genetic privacy would be limited to apply only against government action. The Fourth Amendment right of privacy (the right to be free from "unreasonable searches and seizures") and the more narrow right to "informational privacy" recognized in Whalen v. Roe do not apply to the private sector.[3]

Moreover, the more accurate way to frame the issue of whether statutory law should prohibit or limit disclosure and use of genetic information by private parties is in terms of genetic "nondiscrimination" rather than genetic privacy. It also would narrow the legislative and regulatory focus to consider whether and how to protect consumers from harmful use of genetic information, rather than whether and how to maximize consumers' legal control over that information per se.

But even erecting legal barriers against discrimination based on genetic information would strain the limits of genetic exceptionalism, defy precise definition, pose serious threats to the functioning of private insurance and labor markets, and overlook more effective alternative remedies.

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[3] Fred H. Cate. "Principles for Protecting Privacy," *Cato Journal* 22, no. 1 (Spring/Summer 2002): 54-56.

There is no clear line that separates genetic data from other kinds of personal health information.[4] Attempts to define "genetic" diseases must sort through a fuzzy mix of compulsive, addictive, and patterned behaviors, as well as characteristics like intelligence, aggressiveness, and obesity that have both genetic and environmental roots.[5] Moreover, the sources of legally protected genetic information might be obtained from many current and commonly accepted medical practices that do not involve explicit "tests" of one's genetic material. For example, personal medical histories, family medical histories, routine physical exams, and blood pressure tests all might convey predictive health information that could be linked to genetic factors.

In efforts to protect against genetic discrimination, how should policymakers deal with the "predictability" of medical conditions that are influenced by multiple genes that work in conjunction with environmental factors? Or with genetic predispositions that only increase the risk, rather than establish the certainty, of developing a disease? Or with genetic conditions that increase one's probability of experiencing both adverse and beneficial outcomes? Should legal prohibitions apply only to uses of genetic information that disadvantage the protected party?

Overly broad legal claims to genetic privacy and genetic nondiscrimination often may serve as a subterfuge for more fundamental opposition to various kinds of private health insurance underwriting based on individual health risk or to voluntary disclosure of sensitive health information to one's employer. As Richard Epstein observes, modern uses of privacy may be used to override freedom of contracts and even "act as a handmaiden to fraud."[6] One's right to privacy should not include the right to misrepresent oneself to the rest of the world, particularly in the case of making statements to one's health insurer or employer that one knows to be false, material to the listener, and relied on to the listener's detriment.[7] For example, individual insurance consumers who know or suspect their genetic risk factors should not be able to engage in unilateral

[4] Lawrence O. Gostin and James G. Hodge, Jr. "Genetic Privacy and the Law: An End to Genetics Exceptionalism," 40 *Jurimetrics Journal* 21-58 (Fall 1999).

[5] Colin S. Diver and Jane M. Cohen. "Point/Counterpoint: Genophobia: What Is Wrong with Genetic Discrimination," 149 *University of Pennsylvania Law Review* (May 2001): 1439-1479.

[6] Richard A. Epstein. "How Much Privacy Do We Really Want?" *Hoover Digest* No. 2 (2002) http://www-hoover.stanford.edu/publications /digest/022/epstein.html.

[7] Richard A. Epstein. "The Legal Regulation of Genetic Discrimination: Old Responses to New Technology," 74 *Boston University Law Review* (January 1994): 1-23.

strategic behavior to choose the timing, scope, and/or duration of the insurance coverage they purchase.[8]

A broad prohibition on *any* disclosure of genetic information would prevent good health risks from obtaining positive genetic information on their behalf and then voluntarily disclosing it to potential health insurers. Yet efforts to separate the treatment of predictive genetic information into prohibitive negative categories and permitted positive categories would defy administrative consistency and predictability. They would essentially lead to a regulatory regime of "Can't ask, may tell, may lie" in which truth is discouraged and lies are protected, promoted and necessary.[9]

At this point of the discussion of genetic privacy and genetic discrimination, many private health insurance industry representatives begin to retreat behind the current wall of federal and state legislation that already prohibits or limits most forms of genetic discrimination, particularly in the employer-sponsored group insurance market. For example, the Health Insurance Portability and Accountability Act of 1996 (HIPAA) prohibits discrimination against individual workers who are members of an employer group plan – either on the basis of their current health status or on the basis of their predisposition to a particular disease based on genetic information. They cannot be denied access to group health plan benefits or be required to pay higher premiums due to their individual health status. And, after they have satisfied HIPAA's preexisting condition limitations once, they then may move to another employer's group health plan without facing new limitations on coverage due to additional information about their health status. Genetic information also is treated as protected personal health information under HIPAA's health privacy regulations.

However, HIPAA does not govern the use of genetic information in the individual health insurance market, which generally has more operating freedom in the underwriting process under the insurance rules of most states. Health insurers are more likely to oppose explicit prohibitions on the use of genetic information in the individual market and to point out that tighter restrictions on underwriting and pricing in such a smaller and

[8] See Diver and Cohen, op. cit., pp. 1456-1458, 1466-1467.
[9] Epstein, 1994, p. 14.

often transitory market are more likely to reduce rather than expand available coverage there.

But even medical underwriting in the individual market tends to focus on medical costs that are likely to occur within the first few years after a policy is purchased, and more expensive genetic screening tests to predict much longer range health risks would not be worthwhile to insurers, even if legally permitted. Yet insurance industry representatives generally will caution against outright bans on genetic testing in the individual market, essentially arguing, "We don't use it, we don't plan to use it, but don't prohibit us from using what we don't need to use." One might ask, why?

For one reason, first consider that, apart from HIPAA's legal prohibition on medical underwriting of individuals within employer group health plans, the common practice of insurers is to rely on experience rating for all but the smallest employer-sponsored groups. The expense and administrative burden of more intensive underwriting simply outweighs the practical value of whatever limited and imprecise information about health risk that an insurer might obtain. Insurers also have no incentive to turn away apparently healthy customers, or even somewhat less healthy ones (as long as rating flexibility permits some adjustments), based merely on possible long-term genetic risks that remain hard to measure.

However, it does remain possible that, as genetic testing and genetic information becomes more predictive much further down the road, and as private insurance coverage becomes more customized (such as through defined contribution plans and consumer-driven health care options), more private insurers eventually will face greater pressure either to sort high risks into high-premium and restricted coverage risk classifications or to increase premiums and restrict coverage further across the board. If individual customers become better armed with personal genetic information and can engage in behavior that increases the previously predictable range of insured claims, insurers will want to use, and they will need to use such information to correlate more accurately those genetic characteristics with future costs and premiums. Otherwise, low-risk customers increasingly will exit voluntary private insurance markets and the overall supply of coverage will contract.

A good bit of this speculation about the future and the so-called "end of insurance" reflects the likely time lag we will experience in making a uneven transition from the first round of genetic information and biomedical research that is better able to detect and diagnose genetic problems than later rounds of scientific discovery will be able to cure or mitigate.[10] As Roberta Berry has observed, we should more carefully weigh the consequences of regulatory interventions that essentially are aimed at assuring that genetically high-risk individuals are able to obtain bargain premiums from and transfer their losses to a private pool of lower risk insurance customers or their employers.

Prohibiting use of predictive genetic information also rather "indiscriminately" provides a hidden subsidy to any individual who might be discriminated against for genetic risk reasons, regardless of their financial circumstances or particular needs. Yet we generally do not provide similar subsidies for other forms of "bad luck" in life's genetic lottery, such as less desirable levels of traits like intelligence, aggressiveness, or physical appearance that have at least some genetic roots. It would also seem odd if regulatory treatment were to become relatively more tolerant of adverse treatment of symptomatic individuals than for asymptomatic individuals who merely possess genetic risk factors.[11]

Broad federal regulatory prohibition against genetic discrimination in health insurance may shut off valuable flows of information and suppress financial incentives that could encourage individuals to make better decisions about the insurance coverage they buy, the investments they make in other health-promoting activities, and the behaviors in which they engage.

Not very far below the surface of claims that genetic discrimination in health insurance should be prohibited is the larger issue of whether risk classification based on health status is permissible within at least some private sector portions of our mixed system of voluntary private insurance and publicly financed health programs. Employer group health plans straddle the fence by moving risk classification to the firm, as opposed

[10] See Roberta M. Berry. "The Human Genome Project and the End of Insurance," 7 *Florida Journal of Law and Public Policy* (Spring 196): 205-256.

[11] See Diver and Cohen, p. 1452 (suggesting that HIPAA, the Americans with Disabilities Act, and President Clinton's February 2000 executive order prohibiting genetic discrimination in federal employment already essentially do this).

to the individual level. But private insurers still need to be able to predict the approximate level of health claims they are likely to pay if they are to set their premiums high enough to stay in business, yet assure lower risk customers that the coverage offered to them is worth the price charged.

As enhanced availability and use of more predictive genetic information strains the fault lines of our private health insurance system, we first should consider other market-based, private-sector mechanisms, or at least more explicit and overt public subsidies, as alternatives to expanded regulatory cross subsidies. Public policy might encourage the development of better voluntary pooling mechanisms outside of the employer-employee relationship. It could facilitate long-term health insurance contracts that offer guaranteed renewability options or other time-consistent insurance incentives such as second-tier savings components that would remain subject to illness-state-contingent "severance payments" for early departure from a particular insurance pool. Or consumers might consider purchasing "genetic test insurance" to insure themselves against any as-yet unknown risks before they took particular genetic tests.[12] More conventional approaches might include expansion of high-risk health insurance pools and greater incentives for charitable contributions to nonprofit intermediaries that organize and deliver safety net health care.[13]

I will touch more briefly on the issue of genetic information and genetic discrimination in employment settings (although the above health insurance issues also would come into play for employers that sponsor self-insured health plans). In general, I concur with Richard Epstein's view that employers should be able to seek whatever information they might find relevant to their employee's job performance. Prospective and current employees, of course, may refuse to supply information that is requested.[14] One might imagine some extreme circumstances that could necessitate the intervention of

[12] See, e.g., Tom Miller. "A Regulatory Bypass Operation," *Cato Journal* 22, no. 1 (Spring/Summer 2002): 88-91; Vip Patel and Mark V. Pauly. "Guaranteed Renewability and the Problems of Risk Variation in Individual Health Insurance Markets," *Health Affairs*, August 28, 2002; John H. Cochrane. "Time Consistent Health Insurance," 103 *Journal of Political Economy* (1995): 445-473; Alexander Tabarrok (ed.). *Entrepreneurial Economics: Bright Ideas from the Dismal Science* (New York: Oxford University Press, 2002).

[13] Tom Miller. "Improving Access to Health Care without Comprehensive Insurance Coverage," In *Covering America: Real Remedies for the Uninsured, Vol. 2*. Elliot K. Wicks and Jack A. Meyer, eds. (Washington: Economic and Social Research Institute, forthcoming 2002).

[14] Epstein, 2002.

public authorities to do more than enforce employment contracts and prevent fraudulent misrepresentations, but that should be the narrow exception rather than the broad rule. Irrational prejudice and discrimination in labor markets may overwhelm economic logic on some occasions, but market forces also will impose significant costs on employers who persistently exclude productive workers who might happen to possess genetic risk factors. If employers are faced with prohibitions against using valuable genetic information, they are most likely to resort to other legal and second-best (or third-best) substitutes for forbidden information. Employers might restructure compensation packages to adjust for higher health benefits costs, substitute part-time labor and independent contractors for full-time jobs, rely more on capital investments or offshore operations, or hire younger and presumably healthier workers.[15]

If regulatory policy insists that employers should remain blind to the known costs of employing certain types of individuals, those employers will resort to coping mechanisms to cut their losses but leave us all a bit poorer and less efficient.

Rather than rely on greater regulation of information flows simply because they are labeled "genetic," we should restore and renew our commitment to competitive markets, private property rights, and private contracts.

[15] Diver and Cohen, p. 1459, 1464.