UNDERSTANDING PROHIBITIONS AGAINST GENETIC DISCRIMINATION IN INSURANCE

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ABSTRACT: The justification for laws prohibiting genetic discrimination in health insurance is not at all clear. Neither privacy protection, the distinctive features of health insurance, nor the distinction between presymptomatic genetic tendencies and actually manifested disease provide a justification, although certain practical considerations may justify these laws.


Laws prohibiting or regulating genetic discrimination in insurance are relatively new to the legal scene. Like much legislation directed at recently identified issues, some of these laws have a “ready, shoot, aim” character. Professor Mark Hall’s study of recent legislation prohibiting genetic discrimination in health insurance indicates that many of the affected parties regard such legislation as unnecessary, irrelevant, or both.1 Hall’s paper reveals how laws against using genetic information have affected the health insurance field and how extra-legal norms and self-interest seem to have influenced behavior far more powerfully.

This comment addresses three issues that Hall’s study has stimulated me to consider. First, for the purpose of this symposium, it is useful to understand how

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the laws governing genetic discrimination—which are not expressly about privacy—relate to this interest. Second, a revealing way to assess the force of prohibitions against genetic discrimination in health insurance is to see how analogous prohibitions would operate in life insurance. The differences are significant and can tell us much about the justifications for treating health and life insurance differently. Finally, one of Hall’s findings is that laws prohibiting or regulating genetic discrimination have little impact because such discrimination probably would not occur anyway. At some point, however, this state of affairs may change. At that point we will need to answer the fundamental question of why we should prohibit genetic discrimination by health insurers.

I. THE INTERESTS PROTECTED

The prohibitions against genetic discrimination in health insurance are not expressly directed at protecting privacy. Rather, the apparent object of these prohibitions is to prevent differential treatment of those with and without certain genetic traits. Thus, these prohibitions are designed to allow individuals to purchase health insurance at prices that do not depend on whether they carry various genetic traits. The laws directly prohibit insurers’ use of certain genetic information, but they do not directly safeguard the privacy of that information. For example, insurers almost always know an applicant’s gender, but Title VII has been interpreted to preclude gender-based risk classification in employment-based life insurance and annuities. Likewise, some states prohibit insurers from considering gender when setting premiums for other types of insurance, even though gender is not private or confidential information. Rather than keeping gender information private, these laws simply prevent misuse of gender in the rate-setting process.

Of course, one way to prevent the use or misuse of information, including genetic information, is to ensure that such information is unavailable to insurers or, when available, kept private. At this relatively early stage in the development of genetic testing, concern about genetic privacy is understandable. The eugenics movement in this country and the Nazis’ obsession with racial “purity” are not ancient history. These dark moments in our past heighten fears that genetic information may be misused and fuel the concern for the privacy of genetic information. For this reason, a desirable collateral effect of laws prohibiting genetic discrimination may be to protect genetic privacy as well.

But the difference between protecting against the misuse of information and protecting the privacy of the information itself is worth maintaining. As the amount of genetic knowledge increases, the mystique that now surrounds this area is likely slowly to disappear. Nearly everyone will possess genetic information

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about themselves and will recognize that they have inherited tendencies to suffer certain diseases. We all are presymptomatic and predisposed to *something*. At that point, carrying such a gene will not be a distinctive or embarrassing characteristic, and fewer people will consider their genetic makeup deserving of privacy protection. Genetic information will simply be one sub-category of medical information—private, but no more sensitive than general health history.

As we approach this point, the distinction between the privacy of genetic information and the misuse of such information will come to the forefront. Prohibitions against insurers’ use of genetic information will then clearly be concerned with the use of such information, rather than with its privacy per se. Until we reach this stage, however, we should recognize that prohibiting insurers’ use or misuse of genetic information simultaneously helps to protect the privacy of the information.

II. THE DISTINCTIVE FEATURES OF HEALTH INSURANCE

A variety of factors distinguish health insurance from the two other forms of personal insurance in which insurers might take genetic information into account: life and disability insurance. Each of these factors suggests that, whatever the justification for prohibitions against health insurers’ use of genetic information, those justifications are weak when applied to life and disability insurance.

First, adverse selection is much less likely to pose a problem in health than in life and disability insurance. The vast majority of those applying for health insurance are not applying for the first time. Rather, they are already policyholders who are either switching jobs and therefore switching from one group insurer to another, or holders of individual policies shopping for a better deal. Only first-time seekers of health insurance are at all likely to have concluded that they pose a higher than average health risk. Moreover, the magnitude of a health insurer’s exposure to people who have in fact adversely selected is naturally limited because health insurance provides indemnity only—reimbursement for actual loss. The insurer’s exposure is limited by a policyholder’s policy limits.

In contrast, the threat of adverse selection in life insurance (and to a lesser extent in disability insurance) is far greater. Most life insurance is sold on an individual, rather than group, basis. Applicants must seek coverage, rather than receive it as a fringe benefit of employment. The lion’s share of applicants are therefore seeking coverage for the first time, or seeking additional coverage; very few are merely switching insurers. Moreover, life insurance policyholders always threaten the insurer with adverse selection because life insurance typically is automatically renewable annually at the option of the policyholder. And, unlike health insurance, life insurance has no principle of indemnity that automatically limits the amount of the insurer’s exposure to a policyholder. The only limit is the

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4. Adverse selection is the greater tendency of those posing a comparatively high risk to seek insurance than those posing a comparatively low risk.
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insurer’s judgment regarding the amount of coverage it is willing to sell to any particular applicant.

Second, much health insurance is sold on a group basis through large employers without individual underwriting. There is virtually no selection by these applicants, and therefore no adverse selection. The effect of genetically influenced health insurance costs incurred by a few members of the large group is submerged in the averaging of costs that occurs through group-based experience-rating of premiums.

Finally, I suspect that at least part of the sentiment that favors prohibiting health insurers’ use of genetic information rests on the view that health insurance is substantially different in another important way from other voluntarily purchased private insurance. Private though it may be, health insurance is a major vehicle through which the body politic is moving toward ensuring the universal availability of health care. Consequently, controls on health insurers that enhance the availability of health insurance are often regarded positively precisely because they are a step toward this goal.

Life and disability insurance, however, are much more discretionary, serving as consumption items that different individuals choose to purchase in different quantities. Prohibiting life and disability insurers from screening applicants who pose a serious threat of adverse selection could seriously undermine insurers’ solvency and thereby threaten the availability of these forms of insurance to the rest of the population. For this reason, the benign reaction of those in the health insurance industry to the rise of prohibitions on their use of genetic information cannot be expected from life and disability insurers faced with the same potential restrictions on their use of such information. These latter insurers may well anticipate that in a relatively short period of time they will find such information highly useful and wish to take it into account in their underwriting and premium setting decisions.

These differences between health and life insurance illustrate a more general point—that the degree of refinement of an insurer’s risk classification structure is a function of the interaction of the costs and benefits of refinement. The greater the payoff to the insurer from a greater degree of refinement—including refusing to sell coverage to certain classes of risk at any price—the more willing insurers are to pay to obtain that refinement. One such cost is seeking genetic information, either by inquiring about prior testing or by paying for testing as part of the application process. In the future, the cost-benefit ratio for life and disability insurers may differ significantly from that of health insurers. If that happens, using genetic information will be an important tool for life and health insurers.

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III. WHY PROHIBIT GENETIC DISCRIMINATION IN HEALTH INSURANCE?

There is a natural lottery for skills, talents, and genetic makeup. The differences between individuals that result from this natural lottery are not off-limits to insurers. On the contrary, directly or indirectly, insurers consider many of the results of this natural lottery in their underwriting and pricing decisions. For example, insurers may take one’s health history into account, and that history is at least partly the product of the natural lottery. Auto insurers may take one’s accident record into account, and a person’s accident record is influenced by visual acuity and reaction time, which are results of the natural lottery. So the puzzle is why the law should prohibit health insurers from using genetic information that is the product of the natural lottery—while permitting them to use information that reflects other features of this lottery.

One argument might be that there is a distinction between a presymptomatic genetic tendency and a manifested disease or condition. Some of Professor Hall’s interview subjects suggested that this distinction matters. In their view, taking manifested disease into account in underwriting and pricing is appropriate, whereas taking presymptomatic genetic tendencies into account is not. But the viability of this distinction is questionable. Insurers deal in probabilities all the time. Ordinarily, we are content to have insurance premiums based on probabilities and tendencies no more definitive—and sometimes less definitive—than the probabilities that can be deduced from genetic information.

Perhaps the concern reflected in the prohibitions against genetic discrimination in health insurance is that insurers might give genetic information excessive weight in underwriting and pricing if permitted to consider this information. Professor Hall’s interviews, however, suggest the opposite. His subjects dismissed genetic information as nearly useless, when in fact such information probably has some predictive value. In any event, in the present competitive health insurance market, insurers would lose potentially profitable business if they over-weighted genetic differences between applicants.

Finally, health insurers’ use of genetic information might be thought objectionable because, while predictive, one’s genetic inheritance is not controllable, while other predictive factors used in underwriting and pricing are at least partly within insureds’ control. If that were the justification, however, then we would have to explain why we do not object to health insurers’ use in underwriting and pricing of manifested disease resulting from genetic susceptibility. Why can someone with Huntington’s disease be charged more for coverage when the disease strikes, given that the occurrence of the disease is not within that person’s control?

Although no entirely satisfactory answer is available, part of the answer might be thought to lie in the fact that controllability is often a matter of degree. However, this possible avenue of justification is more complex than first appears. Although one's genetic inheritance is not controllable, the etiology of some genetically influenced diseases is multi-causal. Some people are genetically predisposed to suffer heart disease, but they can influence their condition through exercise, diet, and smoking. Consequently, if controllability were the criterion explaining the difference between mere genetic tendencies and manifested disease, we should expect the law to distinguish between genetic traits that merely predispose an individual to a particular disease or condition if other controllable factors are present and genetic traits that have an impact regardless of environmental factors. Yet the laws prohibiting genetic discrimination in health insurance draw no such distinction, and the fundamental basis for these laws therefore remains puzzling.

Nevertheless, as often happens in law, we can remain uncertain about this deep issue and still identify practical justifications for these laws. Two such justifications are attractive. First, as I suggested earlier, in the future we may have more complete genetic data about the entire population. At that point, it may be considered perfectly appropriate for insurers to consider genetic information, because doing so will not disadvantage a discrete minority of individuals about whom we have distinctive genetic information. The transition to that point, however, may take several decades. In the meantime, scientific advances will be selective and piecemeal. Permitting insurers to consider genetic information gleaned through such advances would disadvantage those whose genetic inheritance we understand early in this decades-long transition period. As the curve of genetic discovery flattens out, however, permitting health insurers to take genetic information into account may become less objectionable. In the interim, prohibitions on using genetic information may make sense.

Second, even if the cost-effectiveness of employing genetic information were to change radically, the major impact of this change would be felt only by small group and individual policyholders. There is no individual underwriting in large group health insurance. Prohibitions on health insurers' use of genetic information thus prevent differential impact on those with individual or small-group coverage.

Given these considerations, the laws prohibiting genetic discrimination in health insurance reflect a general concern of legislators and affected groups that such discrimination may occur, but they are not supported by a recognizable, fundamental ethical principle. Rather, in the end, the proponents of these laws must content themselves with the practical and limited justifications that I have identified.