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Laws Restricting Health Insurers' Use of Genetic Information: Impact on Genetic Discrimination

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Summary

Since 1991, 28 states have enacted laws that prohibit insurers' use of genetic information in pricing, issuing, or structuring health insurance. This article evaluates whether these laws reduce the extent of genetic discrimination by health insurers. From the data collected at multiple sites, we find that there are almost no well-documented cases of health insurers either asking for or using presymptomatic genetic test results in their underwriting decisions, either (*a*) before or after these laws have been enacted or (*b*) in states with or without these laws. By using both in-person interviews with insurers and a direct market test, we found that a person with a serious genetic condition who is presymptomatic faces little or no difficulty in obtaining health insurance. Furthermore, there are few indications that the degree of difficulty varies according to whether a state regulates the use of genetic information. Nevertheless, these laws have made it less likely that insurers will use genetic information in the future. Although insurers and agents are only vaguely aware of these laws, the laws have shaped industry norms and attitudes about the legitimacy of using this information.

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Introduction

Over half of the states have imposed sweeping restrictions on health insurers' use of genetic information (Rothenberg [1995](#); Davis and Mitrius [1996](#); Yesley [1997](#); Mulholland and Jaeger [1999](#)). Similar legislation has been pending in Congress for several years (Colby [1998](#)). Also, in 1996, a federal law known as "HIPAA" (Health Insurance Portability and Accountability Act) prohibited group health insurers from applying "preexisting condition" exclusions to genetic conditions that are indicated solely by genetic tests and not by any actual symptoms (Health Insurance Portability and Accountability Act [1996](#)). This wave of legislation was prompted by a number of reported cases of employers and of health, life, and disability insurers using newfound genetic information to deny coverage, raise rates, or limit the extent of coverage (Billings et al. [1992](#); Alper et al. [1994](#); Hudson et al. [1995](#); Geller et al. [1996](#)). Fear of genetic discrimination of this sort was shown to factor strongly into patients' and family members' decisions and concerns about undergoing genetic testing (Lapham et al. [1996](#)). These laws are thus intended to achieve two kinds of social benefit: (1) to prevent unfair use of genetic information, however accurate that use might be as a source of underwriting information; and (2) to encourage more genetic testing for purposes of research, prevention, treatment, and family planning. This article evaluates only the first objective.

Several distinctive features of these laws must be considered in assessing their purpose and intended effects. First, they typically do not prohibit the use of genetic information from any and all sources. Instead, they usually target only information derived from genetic tests. Thus, many states still allow insurers to consider family history of disease, and they allow insurers to underwrite on the basis of observed clinical signs and symptoms of medical conditions, regardless of their

genetic status. Although a number of states also include information about genetic conditions derived from family history, almost every state prohibits only information about presymptomatic genetic conditions.

The reasons are partly pragmatic, and partly central to the law's purpose (Hall 1996, 1999). Because health insurers have always used symptoms of existing disease in medical underwriting, it would not be feasible and is unjustified to distinguish between diseases with and without significant genetic components. One would either have to prohibit all medical underwriting, which cannot be done as long as the purchase of health insurance is voluntary, or to target only specific sources of information. Information from genetic tests is the sensible point of concern because that is where the fear of insurance discrimination has the greatest discernible impact. Thus, these laws are meant to prohibit health insurers from predicting future health problems that do not currently exist, usually on the basis of genetic test information alone, but sometimes also on the basis of family history. This study is designed to assess how well these laws have accomplished this goal, and whether they have caused any harm.

Although there is fairly wide agreement on what genetic discrimination means (Billings et al. 1992; Yesley 1998), there are substantial differences of opinion on how to apply this definition. The researchers who have documented genetic discrimination consider genetic conditions to be presymptomatic if the condition is mild and the symptoms do not require active treatment, or if the symptoms are more serious but they are being effectively controlled through treatment. These are clearly cases, however, where patients have been given diagnoses suggesting they currently have the diseases, and therefore such patients do not fit our concept of presymptomatic. In this study, we use presymptomatic to mean genetic conditions that are entirely unexpressed, such as predisposition to cancer that has not yet occurred, or presence of the mutation for Huntington disease but without expressed symptoms. There is also definitional uncertainty over which kinds of tests are genetic (Alper and Beckwith 1998). This uncertainty, however, did not affect our analysis and, interestingly, was not raised by any of our subjects as a practical point of concern.

Material and Methods

This is a comparative case-study analysis done in seven states that were selected to pair similar states with and without laws prohibiting health insurers' use of genetic information. Because legislative activity was ongoing throughout this study, the initial selection and pairing was not wholly successful. Three states initially classified as lacking these laws adopted them in 1997, the year after this study was designed. The focus across all of the states is whether practices and perceptions differ before and after enactment of these laws. Groupings of states were compared according to whether they have mature laws (enacted in 1995 or earlier), recent laws (enacted in 1997), or no law (table 1).

Classification	State(s)
Mature laws	Colorado, Minnesota, Ohio
Recent laws	New Mexico, Florida, North Carolina
No laws	Iowa
* North Carolina was used to field-test interview scales and techniques.	

Table 1 Classification of Study States

In each of these primary study states, we systematically interviewed representatives from the Department of Insurance, most of the major health insurers, most of the major centers for clinical genetics, and from three to six insurance agents specializing in health insurance. In each category, subjects with the greatest relevant knowledge and experience were selected. Within departments of insurance, these were either people in charge of public policy, legislation, or compliance. Among insurers, these were actuaries or underwriters for individual (nongroup) and small group insurance products. Agents were selected by contacting professional trade groups and asking for independent brokers who have specialized in health insurance for a number of years. Within the medical genetics community, we interviewed mainly experienced genetic counselors working with adult-onset genetic conditions such as cancer or Huntington disease, but also including those in pediatric or prenatal genetic counseling. In all, we interviewed 12 regulators, 35 people with 23 insurers, 30 insurance agents, and 29 genetic counselors or medical geneticists. We also interviewed five patient advocates and one medical director

from a genetic testing firm. The insurers represented in this interview pool account for over half, and sometimes the vast majority of, the individual and small group health insurance markets in each of the study states. Included are a fairly equal balance among different types of insurers: seven local Blue Cross plans, six local and two national HMOs, and seven national commercial indemnity insurers.

Most of these interviews were conducted in-person and lasted ~1 h. Some agent interviews were conducted over the telephone and some interviews lasted only 15–30 min or were conducted with groups of two to four subjects. Although these semistructured in-depth interviews were based on an interview guide, free-ranging discussions occurred and the coverage of topics varied somewhat among them. Interview subjects gave informed consent and were promised anonymity.

A market testing study was conducted to determine the ability of a fictitious small employer and an unhealthy individual to obtain group and nongroup insurance, following a scripted scenario. An employer with three employees (including herself) contacted 17–18 agents in each of the primary study states to inquire about the availability of health insurance for the group of three, as well as for a group of two plus individual coverage for one employee. The owner of the company, according to the scenario, volunteered that she had tested positive for the breast cancer gene. The "unhealthy" employee had juvenile diabetes, according to the scenario, and the employer was prepared to disclose, if asked, that this employee also has a family history of Alzheimer disease (the Alzheimer information was not volunteered). To avoid violating insurance fraud laws, no actual application forms were submitted. The market testing firm only held one or two phone conversations in which the agent was asked for preliminary information about available products, rate quotes, and an indication of whether the various health conditions would present any difficulty.

We gathered from agents and insurers a selection of 148 application forms from 50 insurers for individual and small group health insurance. Through content analysis, we determined both the level of compliance with genetic discrimination laws and the level of inquiry about genetic information in states without these laws and prior to having these laws. Most of these forms are dated 1995 or later, but a few come from the early 1990s. For most insurers, several forms were examined to cover a range of products, states, and years. (Application forms often vary in minor details from state to state.) Various other sources of documentary information were collected and examined, including underwriting guidelines used by health insurers; informed consent forms and patient information brochures used by medical geneticists; published articles in academic journals and the popular press about genetic discrimination; and unpublished studies based on surveys done at genetic clinics. These multiple sources of information and data were analyzed by using both qualitative and quantitative techniques.

Results

The View from Medical Genetics

We first assess the views of genetic counselors about the extent of insurance discrimination. Genetic counselors are in an excellent position to report on insurance discrimination (Kenen [1984](#); Bowles-Biesecker [1998](#)). Discrimination concerns are frequently a focus of counselors' discussions with patients and families, their clients readily report troubles they face with health insurance at the time of testing, most counselors said they stay in touch with their clients following testing that shows positive (adverse) results, and their clients are prone to contact them even several years later if they encounter difficulties as a consequence of test results. A few counselors, however, said they would not have reason to know if clients experienced discrimination after leaving the clinic.

Of the 29 counselors and five patient advocates interviewed, the great majority said they believe or they have read or have heard that insurance discrimination occurs to a significant extent for adult patients with presymptomatic adverse genetic profiles. They characterize insurance discrimination as a matter of great concern, which they think is widespread or not at all uncommon. They base this view on what they hear at professional meetings or what they read in professional journals. When asked about instances of insurance discrimination with their own clients or those of their colleagues, however, almost every counselor and every patient advocate said he or she knew of no actual cases of health insurance discrimination that

were classified in the way that we used for the purposes of this study. Approximately half had no examples to offer of any type of insurance discrimination, however defined or classified, and said this simply had not been an issue for their clients. Four counselors and one physician with considerable experience said they think the concern over genetic discrimination is greatly exaggerated. Witness these two experienced counselors:

Counselor 1: [After describing a case of a person whose health insurance rates increased because of a family history of Huntington disease, turns to Counselor 2, and says:] "You don't have any cases that you know of?"

Counselor 2: "No, I don't have any. It's a concern that has been brought up in our counseling, but I do not have any documented cases such as that."

Counselor 1: "The deal is, other than this one case, there really aren't any, I don't think it is a really big problem. I think it's an issue, but I think on the scale of all of the things that people have to deal with, I don't think it's rampant. I don't know if that is because insurance companies haven't figured it out or if it really isn't a big problem. I'm unclear about that. I think it's a hot topic and that's where that is. [Counselor 2 has] had more experience. Cancer is different."

Counselor 2: ". . . It hasn't been documented for cancer anywhere, I'm not aware of any documentation in the medical literature for a cancer family that has been discriminated against."

Some counselors gave examples of patients who had trouble getting insurance because of a family history of genetic disease. Most of these also involved situations where there were other clinical indications of existing genetic disease and so were not presymptomatic or purely predictive. Many counselors could only give examples of patients who had trouble getting their insurer to pay for genetic counseling, testing, or preventative services. This was the dominant focus of concern in many of our interviews. Finally, we were given discrimination examples relating to life, disability, or long-term care insurance, or to employment, but not to health insurance.

We heard of only two examples that are somewhat close to the type of genetic discrimination addressed by the health insurance laws. In both instances, a patient asked an insurer to pay for genetic counseling (for cancer testing in one case and Huntington disease in the other), and the insurer subsequently raised their rates, merely on the basis of suspicion of a genetic disorder or the possibility they might take the test, without regard to the actual results of the test. Whether this runs afoul of the state law depends on the precise wording of the relevant statutes. It appears to be more akin to discrimination based on family history, which many states do not prohibit, than based on genetic testing, because only those with a family history have reason to request these tests. This does not lessen the impact of the discrimination, but it means that we were not able to document from genetic counselors that there was any nonambiguous occurrence prior to or after the laws' enactment of the type of discrimination clearly prohibited by most state laws.

Narrowing our focus to precisely this type of discrimination might be criticized for missing the fact that these laws are allowing other types of genetic discrimination to continue that are more prevalent. However, most of the instances of discrimination in underwriting that we documented either do not relate to health insurance (three cases) or are based on symptoms of existing disease (six cases). Only the presymptomatic family history cases are fairly classified as discrimination based solely on genetic information. We heard of four such cases, and two are cases in which health insurers' initial adverse use of family history was corrected with genetic test results that showed absence of the genetic defect. Thus, even if the category of genetic discrimination is expanded to include family history cases, we were able to document only two such cases, and we observed an equal or greater number of cases discussed as follows in which genetic test results were used to resolve health insurance problems based on family history.

The View from the Insurance Industry

To learn the extent of genetic discrimination from within the insurance industry, we interviewed regulators, independent agents, and reliable sources at insurance companies. In each case, there was a consistent view that genetic information is not used in underwriting for health insurance.

Regulators

All of the regulators we interviewed said they could remember no complaints or could document no instances of genetic discrimination by health insurers. These subjects conveyed the attitude that genetics simply is not on their "radar screen" of significant issues in health insurance. Many regulators had no idea what the impetus for the legislation was in their state. Others said the legislation was prompted by a generalized concern to avoid possible discrimination and not in response to any actual cases of discrimination. None of the regulators knew of any cases or history of genetic discrimination occurring prior to the law's enactment, even though, in at least two of these states, a task force or group of advocates devoted extensive efforts to finding evidence of discrimination.

Agent interviews and market testing study

Insurance agents are a highly credible source because they are independent brokers who are paid by commission and well situated and highly motivated to advocate for coverage of their clients and detect any adverse insurer behavior. None of the 30 agents we interviewed could recall any instances of health insurers using genetic test information. Several commented that insurers sometimes use family history information to interpret diagnoses of current conditions, or they remembered instances where clients were treated as having a genetic disease from their symptoms. But none could remember genetic test results ever having played a role in an underwriting decision.

In the direct market test, various aspects of a prepared scenario generated little indication of potential genetic discrimination (table 2). The only difficulty encountered was on account of the individual employee with existing diabetes. Three percent of agents indicated that including the diabetic employee would prevent the three-person group from obtaining coverage, and 25% said this would present some difficulty, such as increased rates or decreased coverage. For presymptomatic conditions, no agent asked about family history of any disease, so the Alzheimer information in the scenario never came to light. When information was volunteered that one person had tested positive for the breast cancer gene, none of the agents indicated this would present a great deal of difficulty, and all of the agents indicated that small-group insurance would still be available (either for a group of two or a group of three) (table 2).



Table 2 Difficulty in Obtaining Small-Group Health Insurance, for Various Conditions

However, 13% of these agents indicated that the breast cancer gene might present some unspecified difficulty, such as increasing the rate somewhat or being subject to a temporary or permanent exclusion of that condition. The testing firm did not record the nature of the difficulty, and it recorded some indication of difficulty even if the agent was unsure or the degree of difficulty indicated was slight. It is often impossible to know for sure how much difficulty a health issue presents until an application is submitted for full underwriting, which was not done here. It is important to observe that this focus on the breast cancer gene was only in the context of small-group insurance, not individual insurance, and that this market test was done after enactment of the 1997 federal law that prohibited insurers in all states from declining coverage to small groups for any health-related reason. Thus, even though this small group had only three members, altering the scenario to a one-person inquiry might have produced a greater indication of possible genetic discrimination.

Whatever difficulty does exist for very small groups, it does not vary according to the type of state law—with one exception. Table 3 displays the degree of difficulty presented by the breast-cancer mutation, organized by various state groupings, to reveal possible differences related to the legal environment. For this purpose, we include two other states, New York and Vermont, which also do not have genetic discrimination laws for health insurance, but which prohibit medical underwriting of any kind for both individual and small group health insurance. Thus, the laws in these two states are even more protective than those that ban only the use of presymptomatic genetic test information (table 3).

Table 3 Difficulty Obtaining Small Group Health Insurance for Person with Breast Cancer Gene

It should be noted that community rating states performed as well as or better than states with genetic discrimination laws, although the differences are not statistically significant. For reasons noted earlier, Iowa is the only study state without either a genetics law or community rating, and there the level of difficulty is substantially greater than for states with these laws ($P < .01$). However, when Iowa is combined with states where the genetics law was enacted the same year as our study, this difference disappears. There is virtually the same level of difficulty in states with mature genetics laws as in those with no or new laws. There are several reasons that this is a valid, and probably more representative, comparison than comparing only Iowa with the other states. First, the states with new genetic laws have the lowest difficulty of all, which is anomalous unless the publicity of the new law affected agents' attitudes. However, as discussed later, most of the agents in our interviews (which is a different sampling of agents than the market test) did not know about these laws, and although the proportion of those who did was somewhat higher in states with new than with mature laws, none of the agents in the market testing study indicated any awareness of these laws, although they were not specifically asked. Even if they were aware, the real inquiry here is insurers' actual behavior, as reflected through the impressions and expectations of agents. For this purpose, the comparison between states with mature genetics laws and those without is more meaningful, because only states with mature laws have an opportunity for agents to establish an experience base under these laws. Finally, to the extent the apparent difference among mature, new, and no-law states is real, this difference is driven by the new-law states and so will likely dissipate as laws in those states become more mature. Thus, the observed effect between states with and without these laws may be short-lived, at best.

Industry self-reports

We spoke to actuaries and underwriters who work with individual and small group products, which are the products that require the most intensive examination of medical records. Uniformly, we heard that all branches of the industry—Blue Cross plans, HMOs, and commercial indemnity plans—do not inquire about genetic test results, do not have a practice of using this information if they come across it in the medical record, and do not include this type of information in their underwriting guidelines. This was the case both before and after these laws were enacted, and both in states with and without these laws. No insurer subject said that their medical underwriting practices relating to genetics were in any way different prior to these laws.

These subjects insisted that, for both business and moral reasons, they are firmly opposed to using presymptomatic genetic test information. Several said this is flatly contrary to their philosophy of proper medical underwriting, which is to focus only on conditions that presently or previously existed, or that it would be ethically wrong to penalize people for genetic defects that haven't yet manifested. Others said they are concerned about the political or public relations backlash that would result from using this type of information, which would be hard to justify because of others' understandable moral or philosophical objections. Still others said the issue simply hasn't come up in any discussions, at any level they are aware of within the company.

Industry practices and sources of information

The strongest confirmation of the credibility of these industry sources comes from two directions: an independent review of the sources and types of information actually collected by insurers, and a convincing explanation of why it is not cost effective to use genetic test results in underwriting. A content analysis of health insurance application forms from 50 insurers found only 2 (4%) potentially asking for genetic test results specifically. One is a commercial indemnity insurer with an extremely detailed application form, which includes one question that reads: Do you have a mental or physical impairment or

deformity, or a congenital or hereditary abnormality, disease or trait not previously disclosed?

We observed this insurer using this question mainly in states without a genetic discrimination statute at the time, although the form appeared to be in use in one state, New Mexico, shortly after the law was enacted there. We saw one other example of this type of question in a state with such a law, North Carolina, also shortly after the law was passed. Curiously, this question was used by the small group purchasing cooperative, which otherwise engages in very lenient medical underwriting. Everyone associated with the organization we asked was puzzled by why this question is included.

On its surface, this question is ambiguous as to whether it requires the disclosure of presymptomatic, predictive genetic test results. "Congenital or hereditary abnormality or disease" clearly speaks to existing conditions, such as birth defects. However, "trait" conceivably refers to mere carrier status or unexpressed disease potential. It is debatable whether this is the necessary meaning. If not, an applicant might be justified in not disclosing such test results, even in response to this question. Agents explained that they are very careful to advise clients about how to provide as little damaging information as possible in response to ambiguous questions on the application. Another reason these two instances of genetic-specific questions do not refute the indications that insurers do not seek out or use this information is that knowledgeable and credible sources at these two organizations, when asked, were not aware these questions were on their application forms. They did not think the information gathered would be used to predict future health problems, but rather to help diagnose present conditions, consistent with practices in the rest of the industry.

We heard repeatedly from agents, insurers, and regulators that using genetic information to predict the onset of future health conditions makes no sense for health insurance because of the short time-frame of reference that typically is used in medical underwriting. Underwriters try to assess only existing or prior health problems based on recent health care utilization because these are the most predictive of likely health care costs in the immediate future. One agent explained that, for small group insurance, "they do a cursory review and they'll look for something that's a full-blown case of AIDS or somebody who's got something that's obviously ongoing and a current concern. They don't try to predict like Methuselah what kind of health care utilization you're going to have in the future."

Near-term medical expenses are the dominant focus as these can be predicted with more certainty, because over time those who begin as higher or lower risks tend to "regress to the mean" by natural laws of probability and because few people keep the same health insurance for extended periods of time. On the latter point, both individual and small group insurers reported a very rapid turn-over in enrollment. The average or predicted length of enrollment was variously estimated at 2–4 years by most insurers, and several estimated that 90% of subscribers will change insurers within 7–10 years. For these reasons, insurers do not consider it very relevant or worth the effort to predict health expenditures 5, 10, or more years into the future for specific enrollees. This is especially true for relatively rare conditions. Conversely, because sick people are very reluctant to change insurance, those who remain the longest are likely to be the highest risks (M. A. Hall, unpublished data).

Strong confirmation of health underwriters' lack of interest in presymptomatic, predictive genetic testing comes from the present use of family history information. Some insurers clearly do use family history information for important disease categories such as heart disease, cancer, and diabetes, but they do so only to look for or evaluate other signs of existing or prior disease, not to predict the onset of future health problems. Five of 23 insurers we interviewed, and 3 of ~30 others for whom we gathered application forms, inquire about family history information in some fashion. Notably, these insurers were spread fairly evenly across segments of the industry: one Blue Cross plan, three HMOs, and four commercial indemnity insurers. Eight of 28 agents recall such questions being asked on health insurance applications. A typical application asks "Do you or your spouse have any biological parent or sibling who has been diagnosed with cancer or heart disease?" One insurer asks about both parents and grandparents, and about any family history of tuberculosis, diabetes, high blood pressure, kidney disease, mental illness, and suicide, in addition to cancer and heart disease.

Agents, insurers, and regulators all said, however, that fewer insurers are asking for this information, that it is usually not used in any fashion even when obtained, or that it is being used somewhat less often. This trend is occurring mainly for pragmatic, not legal, reasons. A number of agents and underwriters were surprised to learn that family history questions

were, in fact, asked on their forms and could not think of any situations where the information had a role in medical underwriting decisions. Those who were more familiar with the use of this information said that it is not used to predict future health problems that currently do not exist, as occurs with life insurance. Instead, family history of disease serves only as a "red flag" for further investigation of a current or previous health problem that has gone undetected, or as a "tie-breaker" in borderline situations. This limitation in use derives both from established industry practice and from regulators' resistance to using this information in a purely predictive fashion. Several subjects noted that regulators would reject using family history in any other way, not because of the recent genetics laws, but on basic principles of permissible medical underwriting for health insurance.

For instance, a 55-year-old person who is overweight and hasn't been to a doctor in a long time might be required, on the basis of a family history of diabetes, to undergo blood sugar testing or a medical examination to rule out existing but undiagnosed diabetes. Similar decisions might be made for heart disease. Or, the health risk of someone with high blood pressure might be evaluated differently in a borderline situation based on the presence or absence of a strong family history of heart trouble. But family history information, no matter how strong, is not used to predict the future onset of disease. Only one person, with a Blue Cross plan, said that family history standing alone might be used to increase rates slightly, perhaps 1%–2% in a very strong case, but this person was a medical director, not an underwriter, and others at the same insurer said this was not done.

The potential for genetic discrimination

Although insurers do not now ask for genetic testing information directly, it is possible, unless prohibited by law, to obtain this information from various sources (Kass 1997; Stone 1997). Insurers could learn about genetic testing from more generic questions about medical visits and diagnostic testing, or from examining medical records or claims for reimbursement. Therefore, we asked health insurers whether, if they happen to learn of positive (adverse) genetic test results, would they use this information in medical underwriting in any fashion, even if the information is entirely presymptomatic or predictive and not diagnostic of current symptoms or conditions. We sometimes asked this question in a general fashion, but we also frequently posed a specific hypothetical, involving breast cancer. We asked what insurers would do if legally permitted to consider information that a woman tested positive for the breast cancer gene and she was 15 years younger than the predicted age at onset.

Approximately half (8 of 17) of insurers who responded to the general inquiry and approximately two-thirds (10 of 14) of those who responded to the breast cancer example conceded that they might or probably would use such information in some fashion, if legally permitted to do so. Also, four of six insurers said that, in the future, it is likely that so much more genetic information will exist and predictive data will be so much more precise that genetic test results probably will be much more relevant to medical underwriting than now. These subjects thought that, whether this information will be used is largely a cost/benefit business decision, in response to market forces. Agents gave similar responses. Ten of 15 agents said insurers might or would use genetic information in some fashion if legal and it came to their attention, and 2 of 4 said use of this information is likely some time in the future.

Many of the insurers were much more tentative, saying they were not sure whether any genetic information would be relevant now, and they would consult their medical director and legal department first before using it. Others said the breast cancer information would have only marginal impact, for instance, raising rates only 1%–2%, depending on the probabilities indicated by existing data. Of the eight agents who were asked the breast cancer question, only two thought insurers would find this genetic information relevant, and in the market testing study, only 11% of agents indicated a 35-year-old person with the breast cancer gene might face some (unspecified) difficulty in medical underwriting for small-group insurance. However, some underwriters said the breast cancer example would be a basis for "ridering out" or "waivering" that condition, not as a generic preexisting condition, but through a specific contractual exclusion of that particular condition. This is usually permissible for individual insurance.

In justifying their possible use of presymptomatic genetic test results, several insurers noted that even the breast cancer

example is not wholly irrelevant to current health care costs. Someone with the breast cancer gene is certain to receive more intensive cancer screening, and may well be a candidate for prophylactic mastectomy. If subscribers expect to be reimbursed for these costs, some insurers insisted that it is only fair they be allowed to consider the results of the genetic tests that prompt these medical costs, even though the person does not currently have the condition. It was also noted that obtaining reimbursement for these preventive services places physicians and patients in a difficult situation. Only existing medical conditions and not preventive services are covered under conventional indemnity insurance. Therefore, it is necessary to declare that a genetic predisposition is an existing condition, much like someone with high blood pressure or cholesterol levels, to claim reimbursement. But, once doing this, it is inconsistent to say that no condition exists for underwriting purposes.

This led us to make additional inquiries. First, we asked whether insurers would regard someone with a genetic predisposition who had not received treatment as having a condition that could be excluded under a generic preexisting condition exclusion. We were consistently told no, both because of HIPAA, and because of generally prevailing concepts of what constitutes a preexisting condition. If a genetic condition has received some preventive treatment, however, half of the insurer and agent subjects asked this question said that it would or might be considered an excluded preexisting condition. This suggests a significant ambiguity in the HIPAA provision. Also, one insurer noted that, although its contracts do not exclude preexisting conditions, it insists that all such conditions be disclosed in the application form, so a failure to disclose a genetic condition that has been treated could be used to void the policy for nondisclosure, without violating HIPAA.

We asked some insurer subjects about a difficult, borderline hypothetical situation involving hemochromatosis. We asked whether, if a patient were found to have elevated iron levels but at a level that does not require clinical treatment, could the patient be regarded as having a preexisting condition based on a genetic test that confirmed that the cause of the elevated iron is hemochromatosis. All five insurers consistently said yes, especially if the physician diagnoses the patient as now having hemochromatosis rather than simply being at risk for the disease. The two regulators who were asked this question puzzled over it and considered it to be a close call that requires further deliberation, but they seemed to lean in favor of the insurers' view.

Thus, there is ample reason to take seriously the concern that health insurers might begin to use presymptomatic genetic testing results. As one genetic counselor noted, the fact that such results haven't been used much to date fails to recognize how recently these tests have come into clinical use, and how rapidly clinical use might grow in the near future. Still, it is notable how disconnected these indications of potential use are from the pattern of state laws that currently exists. Insurers' and agents' responses to the various hypothetical questions and general attitudes just described bear no relationship to the pattern of laws across our study states, nor are they related to the type of insurer represented. This mix of positive and negative views is remarkably consistent or randomly scattered across all study states and all segments of the insurance industry.

Knowledge of and Attitudes about the Law

A final way to assess the impact of these laws on the extent of genetic discrimination is to determine insurers' and agents' awareness of the law and its perceived impact on underwriting practices. All of the state insurance regulators we spoke to were well aware of the relevant state and federal laws. Although they sometimes stumbled on questions about the laws' details, this is because no enforcement issues have arisen under these laws and so they have not been required to look at them closely. In our interviews, regulators were able to quickly locate and examine the state laws when we asked them to consider more subtle or detailed questions.

In contrast, both agents and insurer subjects had only spotty knowledge of these laws. Only 42% (10 of 24) of agents had any awareness there is any genetic-specific law, either state or federal, and almost none had basic, accurate understanding of what state and federal laws say about genetic discrimination in health insurance. Insurance underwriters and actuaries did somewhat (but not a lot), better. Fifty percent (10 of 20) knew there was some genetic-specific legal restriction on underwriting, but most had an imprecise or inaccurate understanding of what the law said. However, their

understanding typically was over-broad, for instance, assuming that the federal law has a broad prohibition, or that state law prohibits the use of family history when in fact it does not. These results can be compared with a similar study in Minnesota of a law prohibiting genetic discrimination in employment, which found widespread lack of knowledge or inaccurate and imprecise knowledge of the law among employment lawyers, occupational physicians, and human resource managers (Rothstein et al. [1998](#)).

None of our subjects believed the genetic discrimination laws have changed underwriting practices for health insurance. As noted above, we detected no changes or differences in application forms for health insurance, either before or after these laws, or between states with and without the laws. Also, none of the national insurers said that their underwriting practices varied among states according to these laws. Instead, they all consistently decline to seek or use genetic test information in any state. Only one subject suggested that, if genetic information were to be used under the various hypothetical situations we presented, this use might differ among states according to what the law allows.

To the extent these laws have had any impact, they appear to have deterred health insurers that might be inclined to use genetic information from even considering doing so. Insurers are split on the legitimacy of using this information. Some believe that this is not morally or philosophically acceptable, whereas others simply see this as a business judgment of whether the economic and political costs of acquiring and using the information are outweighed by the actuarial benefits. Thus, these laws appear to have had some impact in reinforcing the industry's more socially oriented instincts. Subjects with five insurers said their company's practice of not using genetic information was in part a response to a hostile legal environment. These subjects have a general sense there are legal problems with using genetic information, and this reinforced their decision not to use this information or "go down that path." However, these perceptions and reactions are undifferentiated among the states and, as noted above, insurers often overestimate the prohibitive impact of these laws.

Adverse Consequences of Banning the Use of Genetic Information

We also investigated two potential negative effects of these laws. One is whether, by barring insurers from using potentially relevant or important underwriting information, these laws cause adverse selection. The other is whether these laws make it more difficult for people to purchase insurance by preventing them from using favorable genetic test results to establish their good health.

Adverse selection is a term used to describe a situation where insurers do not know as much as applicants do about their risk status. When this situation arises, it can be expected that high risk people will purchase a disproportionate amount of insurance. The problem this creates is not simply a threat to insurers' profits. When insurers expect or experience adverse selection, they are forced to raise their rates across the board to anticipate it, because they aren't able to identify those at higher risk whose rates they should selectively increase. Raising everyone's rates compounds the problem, however, by making insurance less attractive to lower risks. If they drop coverage, average rates go even higher. In the most extreme cases, adverse selection can cause rates to spiral so high that no one wants to purchase the insurance and so the market for that product entirely collapses. More commonly, the market reaches an equilibrium in which insurers can earn a reasonable return even with higher risks in the pool, yet the price remains sufficiently attractive to keep medium or lower risks in the pool. It is impossible to avoid all aspects of adverse selection, because there are always some aspects of risk that motivate insurance purchase yet that insurers cannot feasibly or affordably discover. Low level adverse selection is no more problematic for successful markets than are any number of other minor market imperfections, such as transaction costs and deficiencies in consumer knowledge (Pauly [1985](#)). However, any level of adverse selection will inevitably increase prices somewhat and therefore deter at least some purchasers.

Industry subjects expressed no concern about adverse selection resulting from these laws. Even the insurers with a possible interest in genetic information did not raise adverse selection as the main reason for this interest. Instead, they said they would use genetic information only if doing so would give them a competitive advantage, or if this were necessary to respond to their competitors. This is a much milder response than saying that this information is vital to a well-functioning market. Adverse selection was raised as a potential concern with respect to life insurance. Our subjects appeared to have full

confidence that health insurance would remain a viable product even if insurers were prohibited from using genetic information, as long as the prohibition is applied equally to their competitors. This is a classic "collective action" situation in which everyone agrees that not using genetic information is economically acceptable, but if any one firm starts to use the information effectively, all the others will be forced to do likewise.

We also explored the adverse selection concern by asking genetic counselors whether they explicitly or implicitly encourage this behavior with their clients. Others have reported that genetic counselors warn clients to consider purchasing insurance before undergoing genetic testing, and perhaps also advise them to simply drop the insurance afterwards if they learn from the test results that they don't need it (Pokorski 1997). If true, this would certainly increase the potential for adverse selection. A few counselors acknowledged that part of their counseling was to advise clients to consider their financial situation, including their insurance, prior to testing; however, they don't stress this point very much and they don't suggest dropping insurance later. Only 2 of 11 informed consent forms we reviewed that address adult onset conditions advise patients to consider getting insurance before testing. One says "we encourage you to maximize any life and health insurance coverage before you enter this program" (emphasis in original). Nevertheless, counselors said the focus of this discussion is usually on life and disability insurance, rarely or never on health insurance, because most patients already have ample health insurance. Therefore, we saw no indication that many or even a few people undergoing genetic testing are buying health insurance in anticipation of receiving bad news.

The other potential harm of prohibiting the use of genetic testing information is that people whose results are favorable may be foreclosed from using this to their advantage. For instance, in a state that allows insurers to consider family history but not genetic tests, the insurer might conclude, based on the less precise information, that an applicant is at risk for a genetic condition that genetic testing shows was not in fact inherited. We inquired whether insurers would feel constrained by genetic discrimination legislation from considering the more accurate favorable test results if volunteered by applicants. None of the few insurers we asked had given these issues any thought, so it appears that favorable use of genetic test results has not arisen very often in real world situations. This follows from the fact that insurers usually do not inquire into family history of disease, and when they do they usually don't use this information to predict the future onset of new disease conditions. Nevertheless, there are undoubtedly some situations, such as Huntington disease, where family history has been used adversely, and so this potential exists. The few insurers and regulators who addressed this issue all agreed that, logically, if the law prohibits adverse use of genetic information, it also prohibits favorable use. The few regulators we asked tentatively agreed with this interpretation.

Discussion

The Existence and Potential for Genetic Discrimination

Multiple, independent sources refuted, or were unable to document, any substantial level of genetic discrimination by health insurers, either before or after the legal prohibitions were enacted, or in states with or without these laws. Thus, these laws have had little or no discernible impact on actual genetic discrimination by health insurers because little or no such discrimination is occurring. These findings contrast sharply with previous reports that genetic discrimination is extensive (Billings et al. 1992; Alper et al. 1994; Hudson et al. 1995; Geller et al. 1996; Lapham et al. 1996). Because of this conflict, and because of the inherent difficulty in proving the virtual absence of a problem, we will briefly review the prior studies and summarize the credibility of our sources.

Other studies that report genetic discrimination by insurers have been criticized for overstating the extent of discrimination (Reilly 1997; Volpe 1998). Various defects in different studies include: nonrepresentative or nongeneralizable sampling, using leading questions that invite conclusions of discrimination, failing to distinguish among sources of discrimination, and including both symptomatic and asymptomatic cases. Other studies, which correct many or all of these defects, conclude that discrimination by health insurers is not widespread based on information from presymptomatic genetic tests. A 1994–95 survey of 500 primary care physicians found "only a few instances of refusals of employment or life or health insurance" based on presymptomatic genetic information (Wertz 1997). A survey of 39 fragile-X families in Colorado (most without

affected individuals) found that none had their health insurance canceled or their premiums increased after the genetic diagnosis. Although 6 (26%) of 23 families reported being turned down when they applied for insurance, they each had an affected individual and so did not present an asymptomatic situation (Wingrove et al. 1996). A task force in Ohio, after a thorough survey of insurers, agents, advocacy groups and others, could find no examples of genetic discrimination by health insurers (Ohio Department of Insurance 1995). A survey of 49 health insurers found that all but 1 (i.e., 98%) would insure someone at 50% risk of having the HNPCC (i.e., hereditary nonpolyposis colorectal cancer) mutation for colon cancer and 78% would not increase the premium or limit coverage (Rodriguez-Bigas et al. 1998). Intermediate results were reported from a survey of 103 commercial, HMO, and Blue Cross insurers in 1991. It found that, for most genetic conditions, almost no insurers would decline coverage, exclude conditions, or increase rates based on a family history of various genetic diseases (hemophilia, sickle cell, cystic fibrosis, etc.). However, among various groupings of insurers, 9%–36% would decline or limit coverage for a family history of Huntington disease, and 36%–64% would do so if presymptomatic genetic testing revealed "the likelihood of a serious chronic future disease" (U.S. Congress Office of Technology Assessment 1992).

Our qualitative study is based on multiple perspectives and methods. If health insurers were using presymptomatic genetic test information against applicants or subscribers to any significant extent, it would likely show up in this sample of insurers, agents, and professionals in medical genetics. The 29 genetic counselors interviewed had ≥ 3 years of clinical practice, and many had ≥ 5 years. Included were the directors of genetic counseling at some of the largest, most established, and most prominent centers of medical genetics and research in the country. Although this is the same community that provided information for the earlier published reports of genetic discrimination, our interviews are not necessarily in contradiction, because we in fact heard a number of examples of adverse insurance consequences for people with genetic conditions. But, our more detailed evaluation indicates that, in the vast majority of cases, these most likely are either based more on existing symptoms than on genetic information itself, or they relate to other types of insurance besides health or are concerned with payment for genetic services rather than the availability and pricing of health insurance. These are certainly issues of concern, but they are not the kinds of adverse effects that these laws attempt to address.

Insurers, agents, and regulators consistently verify this account. Because of the suspicion with which many people view the insurance industry, it is important to verify the credibility of these potentially self-serving sources. These subjects were interviewed at length by researchers with knowledge and expertise in underwriting practices and so who were in a good position to probe for more detail and look for possible contradictions or confirmations. We judged these subjects to be candid and credible. On other points, many of these subjects were willing to admit policies and behaviors that put them in somewhat negative light. Very few were defensive or evasive, and many were extraordinarily forthcoming and helpful; the remainder appeared to answer carefully but somewhat guardedly all the questions put to them. Also, the insurer subjects were not spokespersons for their companies who regularly do public relations or lobbying work. Instead, these were career professional actuaries and underwriters who approach these issues in a disciplined and objective fashion and who subscribe to a widely regarded standard of professional integrity, much like CPA accountants. Also, insurers' accounts were confirmed by regulators and independent agents, whose incentives and outlook favor consumers.

These interviews were confirmed by independent and objective sources of information, including a direct market test and content analysis of application forms and underwriting guidelines. If application forms do not ask about genetic test results, and agents know not to volunteer them, then it is unlikely that insurers will learn about them with any regularity. If insurers order complete copies of medical records, they might come across references to genetic testing, but this is now rarely done because of the expense. Also, medical geneticists are careful about how they document these evaluations so as to avoid unnecessarily calling attention to the genetic component. Insurers might learn of genetic testing for those they currently cover if policyholders submit the testing and counseling for reimbursement under their policy. However, insurers are not entitled to learn of the test results, only the fact of testing.

This does not mean that health insurers never have and never will engage in genetic discrimination. Two application forms were discovered with somewhat ambiguous questions asking about genetic conditions or traits. Also, applicants might

feel compelled to volunteer information about genetic testing in response to generic questions about any medical visits or tests of any kind. The insurer whose form is quoted above, for instance, asks "During the past 5 years have you visited a medical doctor . . . for diagnosis, advice, treatment, . . . or consultation not previously explained?" Learning the mere fact of testing or evaluation can itself be very damaging or prompt an insurer to make further inquiry, even if the results are not initially revealed. If not prohibited by law, once an insurer is put on notice, it might ask an applicant or her physician a pointed question about genetic information, which must be answered truthfully to avoid insurance fraud. Also, some forms are designed for both life and health insurance, when companies sell both, and life insurers are more likely to ask about genetic testing. Therefore, there is some opportunity for health insurers to come across genetic information, and when they do, there is some possibility they will use it (U.S. Congress Office of Technology Assessment [1992](#)). We, in fact, documented a few cases of discrimination based on family history.

However, these may well be isolated instances that occurred because of lower level decisions by insurers that do not reflect deliberate corporate policy. We heard of several instances of patients who experienced initial insurance problems that insurers eventually corrected. The institutional inertia or legal defensiveness that often results from justifying an initial decision may make these isolated examples appear more purposeful and insistent than is actually the case in established corporate policy or regular practice. In our interviews, the explanation that family history is used only occasionally and only to obtain more information about existing conditions was heard consistently throughout all parts of the industry and from many credible sources. This was also confirmed by regulators and agents.

Nevertheless, there are several indications that health insurers are interested in predicting future health problems. In response to hypothetical questions, some insurer and agent subjects indicated that having a positive test for BRCA1 or BRCA2 might have some, fairly marginal, relevance in health underwriting, and most subjects conceded that predictive genetic information will potentially be much more relevant in the future. At present, insurers sometimes increase rates for cholesterol levels and tobacco use. Although it was observed that both of these indicators are very common and easy to evaluate, and tobacco use has systemic effects on a broad range of health conditions both in a near and far time span, the same may be true one day for genetic predisposition. Also, genetic predisposition can predict current as well as future medical costs because of the cost of preventive treatment and increased monitoring. Accordingly, genetic predisposition, like high cholesterol and high blood pressure, could become a diagnosable disease category and so be viewed as an existing condition rather than purely presymptomatic prediction. Thus, we do not entirely dismiss the possibility that health insurers might use predictive genetic information.

At present, the explanations of institutional policy opposed to genetic discrimination that we heard in interviews appear convincing for basic economic and statistical reasons. Health insurers do not consider it very relevant or worth the effort to predict health expenditures 5, 10, or more years into the future for specific enrollees. This is especially true for relatively rare conditions, for which little data exist. The dominant focus of health underwriting is on near-term medical expenses. These can be predicted with more certainty because over time those who begin as higher or lower risks tend to "regress to the mean" and because few people keep the same health insurance for extended periods of time.

These basic economic and statistical facts differ significantly for life insurance. It is much more typical to hold onto a life insurance policy for a long time. If a change is made, it is usually to add additional coverage on top of older policies, rather than to replace existing coverage. Accordingly, life insurance underwriting predicts mortality much further into the future, so predictive genetic information is much more relevant to the life underwriting frame of reference. Also, the potential is much greater with life insurance for an adverse genetic test to prompt someone to apply for more insurance coverage. Therefore, it is not surprising or inconsistent to observe that other studies indicate that life insurers have a much stronger interest in knowing genetic test results (McEwen et al. [1993](#)).

The Impact of the Law on Industry Norms

What does one make of a set of laws that respond to a problem that does not presently exist, that are widely misunderstood or not known at all within the industry, and that have little or no discernible effect? One is tempted to

conclude that genetic discrimination laws are "full of sound and fury signifying nothing", or are the result of a "Chicken Little" syndrome by medical geneticists and advocacy groups. There is some merit in these views. However, a more positive view is also justified: There is some potential for health insurers to use genetic information. These laws have solidified the industry's more socially constructive instincts and guarded against socially destructive competitive forces by reinforcing an industry norm that opposes the use of predictive, presymptomatic information in general, and genetic information in particular.

A useful theoretical framework to evaluate and explain the more psychological impact of these laws comes from a growing body of work by prominent legal scholars on the relationship between law and social norms. Social and commercial systems often follow informal norms that completely ignore, contradict, or markedly differ from prevailing law (Ellickson [1991](#)). This displacement of law by social norms should usually be encouraged rather than criticized because social norms often reach a superior result than do legal rules, and they activate informal enforcement mechanisms that are cheaper and more effective than legal enforcement. In other situations, laws and norms interact rather than displace or compete with each other, so that laws often express social values contained in informal norms. Law can shape, create, communicate, or fortify norms (Sunstein [1996a](#) , [1996b](#) ; Shapiro [1994](#)).

This explanation assumes that, even when law has little direct effect on social behavior, expressive or educative laws still can help to alter behavior by shaping social norms. A good example is laws requiring the use of seat belts. Seat belt use has increased significantly after enactment of these laws (Nelson et al. [1998](#)), but this is likely due more to the educative or norm-altering impact of these laws than to simply their legal threat (Bonnie [1986](#); Field et al. [1993](#)). Although people are occasionally cited for not "buckling up," it seems likely that most people who comply do so because the new law helped to educate people about safety concerns, or because the legal prohibition helped to shape a social norm that rejects the prior libertarian attitude in favor of one that regards failure to use seat belts as being socially irresponsible. Thus, compliance occurs, not only because of specific legal enforcement, but also because individual and social attitudes now view not "buckling up" as wrong—wrong not just under the law but according to social norms.

An example of these interactions that relates to insurance is the discrediting of racial classification in all lines of insurance, including health insurance. Wide-spread condemnation of this practice in the 1970s led to rapid and widespread change in industry practices, followed by a spate of state legislation in the early 1980s banning the use of race in all forms of insurance underwriting. One attempting to measure the impact of these laws might find almost none, because the insurance industry had voluntarily ceased using racial factors prior to many of these laws (Wortham [1986](#)). However, no one would say these laws are unwise or unjustified. They express social condemnation and they help to ensure that such practices are not revived. The push for legislation helped to quickly reshape industry norms, and widespread enactment of these laws fortified the new industry norm.

Similarly, genetic discrimination laws have not changed industry behavior but they have helped to preserve the status quo. Even though insurers and agents do not have widespread and accurate knowledge of these laws, these laws have fortified their impression of social disapproval by creating a general climate of legal condemnation. Health insurers avoid the use of genetic information not so much because of the specific threat of law but because the law reinforces the instinct that doing otherwise would be socially wrong. Therefore, health insurers that might be tempted to consider using genetic information have stayed clear of this arena because of an undifferentiated and imprecise sense that it is legally problematic, and insurers that are more philosophically committed to not using this information are not placed in the dilemma of having to respond to competitors that might be tempted to do so.

The insurance industry struggles with competing norms of actuarial fairness and social fairness (Abraham [1986a](#) , [1986b](#)). Actuarial fairness says that insurers not only may, but should, use the best information about risk that is available in order to accurately reflect each person's risk status. Social fairness says that certain types of risk classification unfairly penalize people for factors they cannot control or for which they should not be held responsible. Usually in these debates the industry is univocal in attempting to defend the norm of actuarial fairness; this occurred, for instance, with AIDS testing

(Iuculano 1987). However, in this instance, as with racial discrimination, laws prohibiting health insurers from using genetic information have helped move the industry norm toward social fairness. Whether this has any actual or potential impact on insurers' behavior is not known, however, because insurers were not using presymptomatic genetic information prior to these laws.

Potential Harm

Whether or not these laws, on balance, are a success depends also on an appreciation of their potential harms. It is clear from our interviews that serious adverse selection has not resulted, and is not likely to result soon, with respect to health insurance. This conclusion follows from the prior observations that health insurers do not consider this information important or useful. Barring insurers from using information they do not consider important for underwriting obviously cannot significantly undermine their ability to counter adverse selection. What is more telling is that most health underwriters and actuaries seem perfectly content to accept this ban, both now and far into the future. Many observed that these risks are already in the market, so keeping things the way they are now is not likely to harm the market. By inference, they seemed to suggest (although we did not ask them this) that there is not a large number of people without insurance and at high genetic risk who are waiting to enter the market as soon as they learn their genetic status. In this regard, health insurance differs markedly from life insurance. Many more people lack substantial life insurance, and those with life insurance are able to buy much more coverage if they learn they are at increased health risk. There is only so much health insurance coverage any one person can buy, and most people are already fully covered or unable to afford coverage regardless of their health status.

Another possible harm is the potential for preventing favorable use of genetic test results. Many of the laws enacted so far do not differentiate favorable from unfavorable use but instead prohibit any use of genetic information by health insurers. This is how regulators and underwriters interpret the law, although we only asked a few of them. But how great is the potential for favorable use? None of our insurer or agent subjects knew of genetic information being used in this way, but several insurers, all of those who spoke to the issue, said that favorable use of genetic information is possible and plausible, just as much as the possibility of unfavorable use. The strongest confirmation came from genetic counselors. They gave several instances of clients who had been able to counter adverse family history or misleading clinical indicators by using genetic tests to show the absence of suspected genetic disease.

A few states with genetic discrimination laws explicitly allow favorable use of genetic information, and some others appear to ban only adverse use. Underwriters, however, explain that they cannot look only at the positive side of a potential source of information. They must either consider both sides, or disregard it altogether. This is not only dictated by insurers' notions of what is fair, but by practical realities. Consider, for instance, allowing younger applicants to disclose their age but prohibiting insurers from inquiring about age. Insurers would simply assume that anyone who does not volunteer the information is not young. Therefore, states that want to preclude age discrimination in rating must prohibit any consideration of age, both positive and negative.

Whether the same holds true for genetic information depends on how prevalent it is and whether family history can be considered. For a single, rare condition, it may be feasible to consider only favorable test information because the background risk for the general population is minimal. However, if family history is not being considered, a favorable genetic test for a single disease has almost no impact on one's risk profile, unless it counters misleading clinical indicators. Even when many more genetic conditions become identifiable, distinct genetic risk classes still might not emerge because almost everyone will likely have a number of different elevated risks. We may someday reach a point where significant portions of the population will be able to demonstrate they are genetically favored. Then, allowing favorable use would undermine the goal of preventing wide scale genetic discrimination. Moreover, in states that allow family history to be considered, allowing insurers to consider favorable test results would increase the salience of family history for those who do not volunteer favorable test results and perhaps increase the potential for genetic discrimination. In short, it is wishful thinking to suppose that genetic discrimination can be prevented without inhibiting the use of favorable test results.

A final concern expressed by two insurers is that prohibiting managed care insurers from using genetic information might

make it more difficult to pursue proper medical management of possible genetic disorders, through aggressive monitoring and preventive measures. They were concerned that the prohibition on the underwriting side would be extended to the clinical side of a managed care insurer. This is only a speculative possibility, however, and does not necessarily result from the wording of these laws. It does suggest the possibility, however, that genetic information in clinical records could leak to the underwriting side if there are not sufficient internal protections (Kotval 1998). However, this is mainly a concern only for renewals and rate increases for existing subscribers, and general consumer protections are stronger in these situations than for people initially applying for insurance. Also, most HMOs do not participate in the Medical Information Bureau (which is used mainly by life insurers) and so information in either their clinical or their underwriting files is not likely to be shared with other health insurers. The connection between the clinical and the underwriting spheres of managed care insurers deserves more attention, however.

On balance, although the harms from genetic discrimination laws are not significant, that is because genetic information simply is not much used by health insurers, for either adverse or favorable purposes. But, once adverse uses become possible, so too do favorable ones. At that point, the potential for inhibiting favorable use by clinicians or by those who wish to clear up a suspect family or medical history becomes real, and this potential seems to be roughly as great as the potential for these laws to protect against adverse use.

Conclusion

Laws prohibiting health insurers' use of presymptomatic genetic information were enacted to address the growing concerns that unfair genetic discrimination was occurring and that this was deterring beneficial genetic testing. Here, we show that the first concern was not well founded, confirming some studies but refuting others. Health insurers have little reason to consider future disease states, whether genetic or not, for asymptomatic people and, in fact, have not done so to any great extent, either before or after these laws. Nevertheless, there is some indication that these laws have affected health insurers' attitudes about the social legitimacy of using presymptomatic genetic information and, therefore, they may deter such use in the future. Once these laws become more relevant, however, they may also begin to inhibit other legitimate social and clinical objectives.

Some people may speculate that, by settling for a largely symbolic victory, proponents of these laws have diverted attention from more comprehensive reforms that would achieve universal coverage, but this is highly unlikely and impossible to know. What is more likely is that, at the same time these laws communicated social disapproval to insurers, they may have caused patients and geneticists, without a substantial basis, to take more seriously the threat of discrimination. The ideal protective law would both prevent discrimination without causing excessive collateral harms, and would convey an accurate sense of reassurance. It appears so far that these laws have achieved the first purpose but not the second.

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References

- Abraham K (1986a) Distributing risk: insurance, legal theory, and public policy. Yale University Press, New Haven [First citation in article](#)
- ——— (1986b) Efficiency and fairness in insurance risk classification. *Va Law Rev* 71:403–451 [First citation in article](#)
- Alper J, Beckwith J (1998) Distinguishing genetic from nongenetic medical tests: some implications for antidiscrimination legislation. *Sci Eng Ethics* 4:141–152 [First citation in article](#)
- Alper J, Geller LN, Barash CI, Billings PR, Laden V, Natowicz M (1994) Genetic discrimination and screening for hemochromatosis. *J Public Health Policy* 15:345–358 [First citation in article](#) | [PubMed](#)
- Billings PR, Kohn MA, deCuevas M, Beckwith J, Alper JS, Natowicz M (1992) Discrimination as a consequence of genetic testing. *Am J Hum Genet* 50:476–482 [First citation in article](#) | [PubMed](#)

- Bonnie RJ (1986) The efficacy of law as a paternalistic instrument. In: Melton G (ed) Nebraska Symposium on Motivation. University of Nebraska Press, Lincoln, pp 131–211 [First citation in article](#)
- Bowles-Biesecker B (1998) Future directions in genetic counseling: practice and ethical considerations. Kennedy Inst Ethics J 8:145–160 [First citation in article](#)
- Colby J (1998) An analysis of genetic discrimination: legislation proposed by the 105th Congress. Am J Law Med 24:443–480 [First citation in article](#) | [PubMed](#)
- Davis HR, Mitrius JV (1996) Recent legislation on genetics and insurance. Jurimetrics J 37:69– 82 [First citation in article](#)
- Ellickson RC (1991) Order without law: how neighbors settle disputes. Harvard University Press, Cambridge, MA [First citation in article](#)
- Field JV, Boehm KD, Vincent KM, Sullivan JL, Serafin BG (1993) Individual control of risk: seat belt use, subjective norms and the theory of reasoned action. Risk Issues Health Safety 4:329–341 [First citation in article](#)
- Geller LN, Alpers JS, Billings PR, Barash CI, Beckwith J, Natowicz N (1996) Individual, family, and societal dimensions of genetic discrimination: a case study analysis. Sci Eng Ethics 2:71–88 [First citation in article](#)
- Hall MA (1996) Insurers' use of genetic information. Jurimetrics J 37:13–22 [First citation in article](#)
- ——— (1999) Restricting insurers' use of genetic information: a guide to public policy. N Am Actuarial J 3:34–46 [First citation in article](#)
- Health Insurance Portability and Accountability Act (1996) Stat 1936, Pub L, No 110:104–191 [First citation in article](#)
- Hudson KL, Rothenberg KH, Andrews LB, Kahn MJE, Collins FS (1995) Genetic discrimination and health insurance: an urgent need for reform. Science 270:391–393 [First citation in article](#) | [PubMed](#)
- Iuculano CK (1987) AIDS and insurance: the rationale for AIDS-related testing. Harvard Law Rev 100:1806–1825 [First citation in article](#)
- Kass NE (1997) The implications of genetic testing for health and life insurers. In: Rothstein MA (ed) Genetic secrets: protecting privacy and confidentiality in the genetic era. Yale University Press, New Haven, pp 299–303 [First citation in article](#)
- Kenen R (1984) Genetic counseling: the development of a new interdisciplinary occupational. Field Soc Sci Med 18:541–549 [First citation in article](#)
- Kotval JS (1998) Market-driven managed care and the confidentiality of genetic tests: the institution as double agent. Albany Law J Sci Technol 9:1–25 [First citation in article](#)
- Lapham EV, Kozma C, Weiss JO (1996) Genetic discrimination: perspectives of consumers. Science 274:621–624 [First citation in article](#) | [PubMed](#)
- McEwen J, McCarty K, Reilly PR (1993) A survey of medical directors of life insurance companies concerning use of genetic information. Am J Hum Genet 53:33–45 [First citation in article](#) | [PubMed](#)
- Mulholland W, Jaeger A (1999) Genetic privacy and discrimination: a comprehensive survey of state legislation. Jurimetrics J 39:1–10 [First citation in article](#)
- Nelson D, Bolen J, Kresnow M (1998) Trends in safety belt use by demographics and by type of state safety belt law, 1987 through 1993. Am J Public Health 88:245–249 [First citation in article](#) | [PubMed](#)
- Ohio Department of Insurance (1995) Ohio Task Force on Genetic Testing in Health Insurance: final report. Columbus, OH [First citation in article](#)
- Pauly MV (1985) What is adverse about adverse selection? In: Rossiter L (ed) Advances in health economics and health services research. JAI Press, Greenwich, CT, pp 281–286 [First citation in article](#)
- Pokorski RJ (1997) Insurance underwriting in the genetic era. Am J Hum Genet 60:205–209 [First citation in article](#) | [PubMed](#)
- Reilly PR (1997) Genetic discrimination. American Enterprise Institute, Washington, DC [First citation in article](#)
- Rodriguez-Bigas MA, Vasen HFA, O'Malley L, Rosenblatt MJT, Farrell C, Weber TK, Petrelli NJ (1998) Health, life, and disability insurance and hereditary nonpolyposis colorectal cancer. Am J Hum Genet 62:736–737 [First citation in article](#) | [PubMed](#)
- Rothenberg K (1995) Genetic information and health insurance: state legislative approaches. J Law Med Health Care 23:312–319 [First citation in article](#)
- Rothstein MA, Gelb BD, Craig SG (1998) Protecting genetic privacy by permitting employer access only to job-related employee medical information: analysis of a unique Minnesota law. Am J Law Med 24:399–416 [First citation in article](#) | [PubMed](#)
- Shapiro MH (1994) Regulation as language: communicating values by altering the contingencies of choice. Univ Pa Law Rev 55:681–789 [First citation in article](#)
- Stone DA (1997) The implications of the human genome project for access to health insurance. In: Murray TH, Rothstein MA, Murray RF (eds) The human genome project and the future of health care. Indiana University Press, Bloomington, pp 133–157 [First citation in article](#)
- Sunstein CR (1996a) On the expressive function of the law. Univ Pa Law Rev 144:2021–2053 [First citation in article](#)
- ——— (1996b) Social norms and social roles. Columbia Law Rev 96:903–968 [First citation in article](#)
- US Congress Office of Technology Assessment (1992) Genetic tests and health insurance: results of a survey. Office of Technology Assessment, Washington, DC [First citation in article](#)
- Volpe LC (1998) Genetic testing and health insurance practices: an industry perspective. Genet Testing 2:9–12 [First](#)

- [citation in article](#) | [PubMed](#)
- Wertz DC (1997) Society and the not-so-new genetics: what are we afraid of? *J Contemp Health Law Policy* 13:299–346 [First citation in article](#) | [PubMed](#)
 - Wingrove KJ, Norris J, Barton PL, Hagerman R (1996) Experiences and attitudes concerning genetic testing and insurance in a Colorado population: a survey of families diagnosed with fragile X syndrome. *Am J Med Genet* 64:378–381 [First citation in article](#) | [PubMed](#)
 - Wortham L (1986) Insurance classification: too important to be left to the actuaries. *U Mich J Law Reform* [First citation in article](#)
 - Yesley MS (1997) Genetic privacy, discrimination, and social policy: challenges and dilemmas. *Microb Comp Genomics* 2:19–35 [First citation in article](#)
 - ——— (1998) Protecting genetic difference. *Berkeley Tech Law J* 13:653–665 [First citation in article](#)
-