

SOCIAL IMPLICATIONS OF GENETIC TESTING

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ABSTRACT

This paper examines the social implications of predictive genetic testing and its impact on the insurance industry. Although the Human Genome Project has the potential to improve the health of our nation, it also may serve as a means of highlighting genetic differences among individuals and ethnic groups. Thus, if we are to reach the full promise of the Project, society must address the public's fears of genetic discrimination in insurance and employment contexts. Following an analysis of state and federal legislation on genetic privacy and discrimination, the paper concludes with a challenge to the insurance industry to work with the medical community and health care advocates to formulate a public policy approach that promotes informed consent and the fair use of genetic information.

We have come a long way toward addressing the social implications of genetic testing, but there is still much to do. First, I place genetic testing in a broader societal context, because the members of the insurance industry are struggling to put genetic testing in the limited context of insurance. Next, I present an analysis of the political and economic aspects of the evolution of legislation on genetic testing, as well as some reflections on my own experience in that arena. We can all learn from the messages of this legislative evolution. Finally, I highlight some challenges of genetic testing to the insurance industry.

SOCIETAL THEMES

Keep in mind that, from the beginning, the societal impact of the Human Genome Project was framed in terms of both its promise to the public to improve people's quality of life and its risk—not medical risk, but social. Because of the risks, concern about limitations on the use of the results of tests and fair use of information were raised almost immediately.

To put genetic testing in a societal context, I use five themes. The first societal theme is *genetic myopia* or *genetic reductionism*, a condition in which everything is reduced to a person's genes, leading some individuals to say "It's all in my genes anyway" when contemplating whether they should change their

health behavior. When you get the results of genetic testing, are you going to change your health behavior in a positive way, or will the information so paralyze you that you think the state of your health is fated? If you were a smoker and the test showed that you were predisposed for lung cancer, would you stop smoking to lower your risk, or would you say, "What the heck, I'm going to get it anyway" and start smoking even more? Genetic myopia will have an impact on the insurance system based on the assumptions made about behavior. In the end, genetic myopia, by definition, perpetuates genetic discrimination because central to this myopia is using genetic information to highlight genetic differences among individuals.

The second theme is *genetic testing as a quick fix* where genetic testing becomes an end in itself. This use may make sense to those of you who use predictive testing or genetic testing to help determine the presence of risk, but that is not the intent of the medical model. In the medical model, genetic testing is a means toward an end; the end is to improve the quality of life—to reduce morbidity and mortality. The Human Genome Project was not funded to help insurance companies use genetic testing as a means toward discrimination.

The third theme is that of the *genetic underclass*. This refers not to a person's inability to obtain insurance after being tested, but to the person's inability to undergo genetic testing because he or she cannot access the health care system.

The fourth theme is *genetic accountability*. In some ways this is paradoxical. On the one hand, it is argued "You can't do anything about your genes. They're out

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of your control." On the other hand, undergoing genetic testing has become almost a moral duty, especially in areas such as prenatal testing, where obtaining such information may have an impact on future generations. Do you have a duty to acquire this information because you're accountable to future generations? Once you've acquired the information, do you have a duty to act on it?

Genetic identity is the fifth theme. Genetic information divides humanity into ethnic groups. Watching the media during the last year or two, we have read reports about the Jewish gene for breast cancer. Others report about studying the African-American gene for sickle-cell anemia and the Native American gene for predisposition to alcoholism. Highlighting genetic differences among ethnic groups can breed more discrimination and stigma. We must be sensitive to our past so that we can protect against unfair discrimination in the future. Try to keep these five themes in a societal context as we examine the reaction to genetic testing in terms of public policy on the state and federal levels.

PUBLIC POLICY

State Trends

The evolution of genetic testing legislation began in the 1970s and 1980s when selected states passed antidiscrimination legislation targeted at health insurers and employers. The focus of the legislation was not revolutionary at all, because in many cases it allowed for "fair discrimination." If actuarial justification existed for discrimination, discrimination was permitted; if justification did not exist, it was not permitted. The legislation was also limited to traits such as sickle cell and Tay-Sachs, and not to all genetic diseases.

Those were our early and modest attempts at legislation. At the beginning of the Human Genome Project came preventive legislation. People feared they would suffer discrimination because of the results of a predictive genetic test. The challenge was to develop a strategy to allow the Human Genome Project to move forward with the support of legislation that addressed potential discrimination and privacy concerns.

The first states to create preventive legislation limited the health insurance industry to assessing risk without asking individuals to undergo genetic testing or to reveal the results of any tests that might have been performed. This was very significant, because if someone had been in a research protocol, the information might not have been in their medical record,

but if they were asked on an application and responded, the information would be available to insurers. With this legislation, insurers could not ask specifically for genetic test results, or if the information was somehow obtained, they could not use it to determine rates or coverage. This legislation changed the rules of the game for medical underwriting. The natural progression of this legislative evolution is reflected by the fact that a majority of states now have laws on the books or bills proposed to address discrimination and privacy of genetic information.

Federal Trends

While this was going on at the state level, the federal government passed the Health Insurance Portability and Accountability Act of 1996, which provided specific language about genetic information in the generic health reform law. First it specifically stated that genetic information, like all other information on health status, cannot have an impact on insurance eligibility or continuing eligibility, although some room was allowed for preexisting conditions. Second, and most significant as a message of social policy, is its definition of genetic information in the context of preexisting conditions. It stated that in the absence of a diagnosis related to a specific condition, no preexisting condition is present. For example, if a healthy woman undergoes a genetic test for breast cancer, learns the result is positive, and then develops breast cancer, she is not deemed to have a preexisting condition that would limit her coverage or benefits. The woman was healthy when she purchased the insurance even though she had a positive test result.

What effect this is going to have on the future of insurance is not clear, but it certainly makes the societal statement that a particular person is not "pre-cancerous," "presymptomatic," or pre-anything. A person is still healthy but now has information about whether or not he or she has a certain genetic mutation or predisposition.

Many of the comprehensive genetic discrimination and privacy bills in 1997 are characterized by bipartisan support. Clearly, genetic information is different from cholesterol levels or other family history information because it can actually prevent an individual from getting a job and may result in societal ostracism. The bottom line is that the sensitivity associated with family history and genetics and ethnic groups does have an impact on society. Those of you in medical research know that the legacies of Tuskegee and Nazi Germany are still with us. Rational or irrational,

people like to note differences, and that can have unfortunate consequences. The sensitivity around genetic testing is tied to the perception that those consequences may affect not only you but also your family and your ethnic community.

SOCIETAL CONCERNS

The public is sensitive to genetic testing potentially leading to what, in insurance jargon, is called "fair discrimination"—discriminating against a healthy individual who undergoes testing to improve his or her health but receives a positive test result. Fair discrimination may sound great to the insurance industry, but it does not sound as great to the public. If you want to retain this discrimination in the life insurance business, come up with another name for it, because those two words together, "fair discrimination," do not make sense to the public.

Another concern about use of genetic information is its ties to race and sex. As a society, we have decided not to use race as a factor in underwriting, but we have decided in some circumstances to use sex. Like all genetic characteristics, at this point we control neither our race nor our sex. In this argument, excluding uncontrollable factors from underwriting seems to be the more common route. If this is the case, genetic testing should be treated in the same manner: the results of the test are not controllable and should therefore be excluded.

Another area to reflect upon is the political decision that as a society we are not going to deal with all the issues raised by genetic testing, only with the one that we consider to be highest priority, namely, access to health care. Misfortune should in no way prevent an individual from benefiting from and accessing the health care system. That is a very powerful political reality. But what about legislation on disability and life insurance? In almost all the states that had initial proposals to include disability and life insurance within an insurance discrimination and genetic privacy bill, legislators determined to address only health insurance. In some states, bills have not passed precisely because legislators will not on principle back bills that exclude disability and life insurance.

Political and Practical Realities

In many states, the health insurance companies have actively fought these bills, but the life insurance companies have testified against them, even though they contain nothing about life insurance, which angers legislators. In response, life insurance companies have

said that they do have a role in such legislation because, if passed, the next step is legislation that will regulate life insurance companies. They are in essence stating their view that preventing access to genetic information sets a bad precedent as a matter of public policy and that they will return, fighting even harder, when life insurance legislation is on the table. The warning here is to be very careful about the battles you fight on the state level.

One example is Arizona's effort to pass a law encompassing health, long-term health, and disability insurance. The house passed it almost unanimously; the senate passed it, but without unanimity; and the governor was hedging. Unfortunately, a few life insurance companies in the disability and long-term health insurance market threatened to leave the state if the bill was passed. The next morning, the governor told the press, "I am genetically indisposed to being threatened by the insurance industry. I'm signing the bill." In the context of politics, the message here is that threats are not very constructive in advancing your position.

In some states I might speculate that the health insurance industry did not fight this legislation because of other insurance legislation already in place. Many states had passed strong health care reform legislation affecting traditional health insurance. With the onslaught of managed care organizations, the health insurance industry suffered tremendous attrition. The proposed insurance legislation was not perceived as having much of an impact on the individual market, so in many cases the health insurance industry saw no need to mount a major fight. When the health insurance industry did fight back, states still were able to pass laws, because this type of legislation has many strong advocates, including the breast cancer community, women's health advocates, the medical establishment, the research establishment, and the taxpayers who are funding the Human Genome Project. Furthermore, biotech companies recognized that they needed some form of legislation to market testing to a public that would be assured that they were being protected from potential discrimination.

CHALLENGES

The research and medical establishments are intimately linked to the Human Genome Project. The medical establishment has remarked at state and federal hearings that they are being forced to do things that make them uncomfortable, such as not including genetic information in medical records because of

their patients' fears that the information will be used against them. They wonder whether their actions are unethical. Where are we in society if people can't be honest with one another? What is our ultimate goal as a society? I think this is a real challenge for us. Another challenge is to establish coalitions to educate the public, health care providers, and the insurance industry about some of the needed trade-offs. While legislation offers some protection to individuals, I worry about the market, especially the biotechnology community, using these advances in antidiscrimination legislation as marketing tools to assure the public that they should undergo genetic testing because the information will be protected.

But testing has its limits. Keep in mind that the predictive value of genetic testing is not determinative. Much data are still in the research stage, and using or misusing data to sell products and services is bad business. To reach good risk classification, achieve actuarial fairness, and perform good underwriting—all the things that are at the core of good insurance business—you need good data. But you don't necessarily need predictive testing to decide who will and will not be covered, because this testing just isn't good enough. For example, it is possible that two women with family histories of breast cancer visit genetic counselors. Following their respective sessions, one decides to undergo genetic testing and the other does not. The woman who has the genetic test done finds out that she has the genetic mutation for breast cancer and lives the rest of her life with the fear that one day she will develop cancer, but she never develops it. The other woman, not having the "definitive" results, goes along without the fear but does develop breast cancer. As you can see, not only did the genetic information not benefit the insurance company, in this case it adversely affected the life of the person that had the test done. This is why only the individual, and not an insurance company, should determine whether or not he or she wants to obtain genetic information.

Those in the life insurance business who believe you have a right to genetic information are in for a

challenge. Research ethics forbid researchers from doing harm to individuals by recruiting them into protocols. But if individuals cannot be assured that their research records are private, what is their incentive to participate?

While certificates of confidentiality in research forbid the subpoena of research data, nothing specifically prevents insurers from asking an individual whether he or she has been a research subject and what the results of that research were. Although state laws may provide some protection, there is no uniform law addressing genetic privacy and discrimination. Maybe every area of insurance would be better off if a federal law was passed universally to prevent acquisition and misuse of genetic information. That would level the playing field.

The area of insurance coverage and genetic testing presents many challenges. It is important that we keep the dialogue open, change the insurance jargon that is offensive to the public, do more research on the possibilities and the future of genetic testing, survey public attitudes regarding perceived fear of increased rates or cancellations from genetic tests, and educate the public. We all need to obtain better information in order to move forward.

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