Genetic privacy and confidentiality have both intrinsic and consequential value. Although general agreement exists about the need to protect privacy and confidentiality in the abstract, most of the concern has focused on preventing the harmful uses of this sensitive information. I hope to demonstrate in this article that the reason why genetic privacy and confidentiality are so difficult to protect is that any effort to protect them inevitably implicates broader and extremely contentious issues, such as the right of access to health care. Moreover, the tentative legislative and policy steps undertaken and proposed thus far have been, for the most part, misguided, simplistic, and ineffective.

DEFINING PRIVACY AND CONFIDENTIALITY

As I use the term privacy, I am referring to the limited access to a person, the right of an individual to be left alone, and the right to keep certain information from disclosure to other individuals. Privacy would encompass an individual’s right to decide whether to receive certain information about himself/herself from a third party. It would also involve the circumstances under which the individual shares information with others, such as family members, health care providers, or entities with a financial interest in the individual’s current or future health, including an employer or an insurer.

By contrast, with confidentiality I am referring to the right of an individual to prevent the redisclosure of certain sensitive information that was disclosed
originally in the confines of a confidential relationship.³ The paradigmatic confidential relationship involves the patient and physician. With regard to genetics, the central question is: How can the confidentiality of genetic information be protected? In other words, is it possible to keep certain information a patient has given to a physician or a physician has developed from getting to a third party? Generally, most commentators and legislators have proposed erecting a barrier between the physician and the third party, limiting what, when, and how the physician may disclose genetic information about a patient to a third party. Accordingly, a variety of proposals have been put forward to limit access by computer, to impose requirements for express, written consent before the physician may disclose information, and to give the patient notice of each disclosure.⁴ I believe that measures to protect against the unauthorized disclosure of genetic information are necessary but not sufficient to protect genetic privacy and confidentiality. Furthermore, this approach is fundamentally flawed if it is to be used as the primary method to protect against the involuntary disclosure of genetic information.

If a third party has enough leverage and economic power, it can go to an individual and require him/her to execute a release that authorizes a physician to release the medical records to the third party. Even if a law were enacted to prohibit physicians from ever disclosing the information (even with a release) to a third party, the law still would be ineffective. If the information were sufficiently important to a third party, that third party could require an individual to get a copy of his/her medical records, and to submit them directly to the third party along with the application for matters such as employment, insurance, or a mortgage. In addition, if a third party really wants the information, it may simply require an individual to provide a blood sample that the third party can test. With the emergence of multiplex and chip-based DNA tests, it will be increasingly quick and inexpensive for third parties to perform genetic testing themselves.

I believe less emphasis should be placed on regulating the procedures for disclosure of information by physicians and other holders of medical records and more detailed focus placed on the circumstances surrounding the acquisition of the information by third parties. Who are these third parties? What need do they have for the information? And what are they going to do with the information? In other words, what substantive rights of the individual are implicated by a third party’s use of genetic information? It is apparent that a third party’s needs and rights are going to vary tremendously depending on whether it is a health insurance company, a life insurance company, a disability or long-term care insurance company, an employer, a school, a mortgage company, a law enforcement agency, a court, or some other third party. That is why protecting genetic privacy and confidentiality is more complicated than some people have asserted, and these numerous applications cannot be resolved by a general procedural law.

HEALTH INSURANCE

As of 1998, laws have been enacted in over half the states to prohibit health insurance companies from requiring genetic tests as a condition of coverage or from denying or charging higher rates based on the results of a genetic test(s). A typical provision reads as follows:

No insurance company may require genetic testing or use the results of a genetic test to deny coverage or increase the rates for health insurance.

When these laws were enacted, many legislators and advocates believed that major strides had been made in eliminating genetic discrimination. Unfortunately, a closer examination reveals a problem. The laws only apply to individuals who are asymptomatic. Once the individual becomes symptomatic, the laws do not apply. For example, in a state with such a provision, an insurance company cannot use the positive result of a test to detect a genetic predisposition to breast cancer to deny coverage while the woman is asymptomatic. If she becomes symptomatic, however, then the insurance company can cancel the policy or increase the rates 100 percent or more, depending on the provisions of the state’s general insurance laws.

To improve the effectiveness of the law, the following amendment would help:

No insurance company may use the results of a genetic test to deny coverage or increase the rates for health insurance for an individual who is asymptomatic or symptomatic.

This amendment would eliminate the problem of the woman who is asymptomatic when she applies for the coverage and then develops genetic-based breast cancer. The problem is that only a small percentage of breast cancers (about 5 percent) are known to be caused by genetic factors.⁶ Why should the law treat women who have breast cancer caused by a genetic factor, 5 percent, different from the 95 percent of women whose breast cancer results from unknown causes?

The unfairness and illogic of such a law can be remedied by the following proviso:

An individual, who is symptomatic for a condition for which a particular genotype may increase the likelihood of getting the condition, shall not be denied coverage or assessed higher rates, whether or not the individual’s condition can be shown to be caused by genetic factors.

The law now would protect women who are asymptomatic and carry one of the alleles predisposing them to breast cancer; it also would protect all women who get breast cancer, regardless of the cause.

This version of the law is better, but it still suffers from a major weakness. Is it logical to protect women with breast cancer from discrimination in health insurance, but not to protect the women (and men) who have infectious diseases, who are victims of assault, who have an occupational disease, who are injured in an automobile accident?
in car accidents, or have other serious medical needs? Does it make any sense to draw a distinction between these classes of people who need health care coverage?

To remedy the problem of favoring one group of individuals in medical need over another in terms of access to health insurance, the following law could be enacted:

No insurance company may deny coverage or increase the rates for health insurance based on an individual's past, present, or predicted future health status.

Clever readers, no doubt, already have detected a problem with this version. This law can be classified as guaranteed issue, guaranteed renewal, community-rated health insurance. Under it, health insurance companies may not discriminate in policy issuance based on health status, they may not cancel coverage as long as the premiums are paid, and they must renew the policy without discrimination at the same rate.

The problem with this type of system stems from its optional nature. The essence of community rating is that low-risk people subsidize high-risk people. Over time, the low-risk people may become high-risk, but in those years they will be subsidized by someone else. In a community-rated system, the premiums of low-risk people will rise. Low-risk people tend to be younger and with lower incomes. They may not be able to afford the higher premiums or they may think that, because they are currently healthy, their discretionary dollars could be better spent. When low-risk people drop out of the pool, rates rise for the remaining individuals, which causes more low-risk people to drop out, and the pool increasingly is filled with older, sicker people. Eventually the system collapses.

To avoid the problem of people leaving the system, participation must be mandatory. The only logical solution, then, is a mandatory participation, guaranteed issue, guaranteed renewal, community-rated health care system. In theory, this would produce a fair health care system that would not discriminate against individuals based on genetic predisposition or other factors. Nevertheless, during 1993 and 1994, the U.S. Congress decided that any "universal access" health care system would not be in the best interests of the country.

In light of the illogic at the starting point and the intransigence at the concluding point of this exercise, is it possible to prevent genetic-based discrimination in health insurance within a system that is unfair and illogical? Unfortunately, the answer is no, unless and until the United States is prepared to address in a comprehensive way the larger issue of who has access to health care. In the interim, we are left to decide what form of illogical, suboptimal health care tinkering makes us feel as if we have resolved the issue of genetic discrimination in health insurance.

The inability to solve a fundamentally flawed system through incremental approaches raises important issues of politics and advocacy. One wonders whether it is efficacious, tactically sound, or ethical for genetic advocacy groups to promote legislation prohibiting genetic discrimination in health insurance (or other areas) when the laws have so little value to those at risk of genetic disorders and no value to those who have illnesses from other causes. Indeed, such legislation may even result in further stigmatizing genetic conditions and fragmenting support for meaningful health care reform.

**LIFE INSURANCE**

The use of genetic information in other types of insurance also places genetic privacy and confidentiality in the context of substantive interests. For example, life insurance companies are in the business of assessing and classifying risks, primarily on an individual basis. Traditionally, life insurance companies either refused coverage or assessed higher premiums for individuals who were currently ill, had a history of serious illness, or who had risk factors, such as cigarette smoking, substance abuse, obesity, or hypertension, that negatively affected their life expectancy.

With the development of predictive genetic testing, individuals who are presymptomatic for late-onset, single-gene disorders can be identified, and the information can be used in medical underwriting. Furthermore, life insurance companies, fearing adverse selection, also use the results of genetic tests along with family health histories in applicants' medical records. Yet, the number of individuals with late-onset, single-gene disorders is quite small. The real challenge of genetics and life insurance involves more common multifactorial disorders, such as breast cancer, ovarian cancer, and colon cancer. Although mutations associated with an increased risk of these disorders have been identified only recently, some life insurers have begun using this predictive information in medical underwriting.

Two policy issues have been raised by insurers' use of predictive genetic information. The first concerns the accuracy of the predictions. Although some morbidity data have been developed for these predisposing mutations, it is still too early to develop any meaningful mortality data. For example, individuals with a genetic predisposition to colon cancer may undergo frequent colonoscopies, thereby detecting cancer in its earliest, treatable stages. It is not clear what the mortality risk for such a cohort would be. Thus, considerable risk exists that underwriting decisions could be based on incorrect data.

The second issue will arise with even greater force when predictive mortality data are better developed. It involves the role of life insurance in society. Is life insurance a purely commercial relationship, an estate-building investment vehicle, and an income-replacement arrangement? If so, it is reasonable to
permit life insurers to have access to any information they want in underwriting, so long as their decisions are actuarially justified and medical information is kept confidential. On the other hand, if life insurance has some other social value, such as preventing social disruption caused by the death of the primary wage-earner in a family, then it is reasonable to regulate the information on which underwriting is based and thereby the availability of the insurance product.

State legislative activity dealing with genetic information and life insurance has increased in the last few years. Seven states have enacted laws requiring informed consent for using genetic information. Eight states also have laws requiring that medical underwriting based on genetic factors be based on actuarial principles, although actuarial determinations by insurance companies traditionally have been given great deference by state regulators. Proposed legislation in at least three states would prohibit the use of genetic information in life insurance for policies below a certain dollar amount or altogether.

As with health insurance, it is simplistic to say that restrictions on a life insurance company’s access to genetic information will protect the privacy and confidentiality of genetic information. It is necessary to probe the underlying assumptions about the role of life insurance in contemporary American society.

**LONG-TERM CARE INSURANCE**

Private long-term care insurance is likely to become increasingly important over the next ten years. Currently, only about 25 percent of nursing home care is privately financed. Medicaid pays for a substantial portion of the care of individuals who have spent down their assets and meet eligibility standards. The combination of federal Medicaid cutbacks, growth in the elderly population, and the low ratio of potential caregivers to care-receivers means that private long-term care insurance will become increasingly important.

The profitability or solvency of insurance companies and long-term care institutions selling long-term care policies is threatened by the prospect of individuals needing skilled nursing services, but surviving for many years. Alzheimer’s disease represents the biggest risk. Already, researchers have identified genetic factors with a link to Alzheimer’s disease, and long-term care insurance companies will have a strong interest in obtaining the results of such tests or performing the tests themselves in advance of offering coverage.

Many states already prohibit nursing homes from discontinuing the treatment of patients with Alzheimer’s disease or from discriminating in the treatment of such patients. Legislation in Colorado, however, goes a step farther by prohibiting any use of genetic information in long-term care insurance, and other states are considering the issue.

The development of public policy on long-term care insurance depends to a large extent on whether long-term care is viewed more like health insurance or life (and disability) insurance. If the former, then more individuals would regard it as a necessity or a right to which all individuals, regardless of their medical histories or genetic predispositions, should have access. If the latter, then it is more likely to be considered an optional commercial transaction, and all parties may require access to any information deemed relevant. Again, the privacy and confidentiality interests of individuals depend on the substantive issues of entitlement or eligibility for insurance.

**EMPLOYMENT**

Employer coverage is extremely important in terms of how people get their health insurance. Employers may want to know the genetic make-up of employees to prevent occupational injury and illness or because of concerns about productivity, absenteeism, and turnover. But the number one reason why employers would want access to genetic information about applicants and employees is health insurance cost containment.

Employers often pay at least $5,000 per year per employee for health insurance. In some industries and in some companies, where the benefits are more generous, the cost may be much higher. In any given year, 5 percent of health care claimants consume 50 percent of health care resources, and 10 percent of claimants consume 70 percent of resources. It quickly becomes clear to health benefits managers that if they can eliminate a class of very high-cost users, they are going to save the company a lot of money. And those high-cost users do not even have to be employees; they can be the dependents of employees.

The primary federal law prohibiting discrimination in employment on the basis of health status is the Americans with Disabilities Act (ADA). Medical examinations under the ADA may be divided into three parts, based on when they are performed. At the preemployment stage, when the employer considers the individual’s background and qualifications, medical inquiries and examinations are not allowed. An employer is prohibited from performing a medical examination, asking about the use of prescription medications, asking about the use of sick leave, or similar matters. The employer is limited to asking whether the individual has the ability to perform essential job functions. For example, if essential to the job, the employer may ask whether the individual can climb telephone poles, has a driver’s license, or is able to stand for long periods of time.

The key stage is the second. The ADA permits employers to make offers conditioned on a satisfactory report following a post-offer (“employment entrance” or “preplacement”) medical examination. The medical examiner may be a company-paid, full-time employee or, more often the case, an independent consultant. The ADA places no limitation on the scope of this examination.
Except in the states where prohibited by a specific law, an employer may even require genetic testing.

Most significant, under the ADA, the employer may require, as a condition of employment, that a conditional offeree sign a blanket release, authorizing the disclosure of all of the individual’s personal medical records to the company for review. My fear is that employers are going to perform genetic tests themselves; it is currently not cost effective to do so. But employers can get access to the results of genetic tests performed in the clinical setting as well as family histories contained in personal medical files. This fact not only raises the prospect of discrimination, but it also discourages at-risk individuals from undergoing possibly beneficial genetic testing. Thus, a close nexus exists between the confidentiality of genetic information and public health objectives.

Even if a law were enacted making discrimination based on genetic information illegal, we have to assume that some employers that could lawfully get access to the information would then illegally use that information. In 1964, almost thirty-five years ago, Congress enacted Title VII of the Civil Rights Act of 1964, which made it unlawful to discriminate in employment on the basis of race, color, religion, sex, and national origin. In 1967, the Age Discrimination in Employment Act added age to the list of proscribed forms of discrimination. Despite these laws, it is obvious that discrimination based on these factors continues today. Yet, discrimination on the basis of criteria such as religion or national origin does not save employers any money. Discrimination on the basis of health status or perceived health status, however, could save hundreds of thousands of dollars on a single individual’s health insurance claims. Therefore, we have to assume that at least some employers that would have access to genetic information would use it.

With regard to medical examinations and records of current employees, once the individual has started working, the employer may only require employees to undergo examinations that are job-related. Voluntary examinations and wellness programs of a broader scope are also permitted.

In March 1995, the Equal Employment Opportunity Commission (EEOC) issued an interpretation regarding the applicability of the ADA to genetic discrimination. According to EEOC, covered entities (that is, employers) that discriminate against individuals on the basis of genetic predisposition are “regarding” the individuals as having a disability and therefore the individuals are covered by the third prong of the definition of individual with a disability under the ADA.

EEOC’s statement is of limited value for three reasons. First, EEOC interpretations are not binding on the courts, and the issue has not yet been addressed by any court. Second, the interpretation does not apply to the unaffected carriers of recessive and X-linked disorders, who might be subject to discrimination by employers concerned about the health care costs of future dependents. Thus, it would not be unlawful for an employer to discriminate against an individual whose carrier state created a risk of having a child with Duchenne muscular dystrophy or cystic fibrosis. Third, and most important, EEOC’s interpretation does not prohibit employers from requiring as a condition of employment that an individual sign a broad medical release, thereby giving the employer access to clinical records that could contain genetic information.

Nearly every state has considered legislation prohibiting genetic discrimination in employment. As of 1998, eighteen states have enacted laws providing that no employer may require genetic testing or may use the results of a genetic test or genetic information to discriminate in employment. Unfortunately, these laws are inadequate. In general, they define “genetic discrimination” too narrowly. For example, Texas enacted a law in 1997 prohibiting employment discrimination based on genetic information, and genetic information is defined as the results of a DNA-based test. Therefore, it would not violate the law for an employer to discriminate against an individual because his/her medical record contains a remark that “father died of Huntington disease.”

A related, insurmountable problem, is defining genetic. Recent research has identified genetic associations with diabetes, epilepsy, hypercholesterolemia, hypertension, osteoporosis, and numerous common disorders. It is not clear whether information about such disorders is genetic information. From a medical standpoint, distinguishing genetic from other medical conditions is increasingly impossible, even though this significant fact has yet to be appreciated in the policy debates.

Another major limitation of these state laws is that they do not prohibit employers from compelling medical releases, thereby permitting employers to gain access to genetic information in medical records. Finally, the laws do not prohibit employers from getting genetic information through employee health insurance claims. Self-insured employers, in particular, may obtain a tremendous amount of individually identifiable information through health insurance claims, and little has been done thus far in the way of regulating that access.

Three main options are available to address the issue of genetic discrimination in employment. First, the ADA could be amended to prohibit employers from obtaining non-job-related medical information. It is doubtful, however, that this or any other amendment of the ADA would be given serious consideration by Congress, because the ADA’s supporters (who would seem to be the likely sponsors of such an amendment) are afraid that, if the ADA were subject to amendment, ADA opponents would offer their own amendments to weaken the Act.

Another possibility is to enact a state law to prohibit access to non-job-related medical information. In 1983, Minnesota, enacted a law providing that all employee medical examinations, no matter when given, must be strictly
job-related and consistent with business necessity.24 Also, if an employer uses medical information from an applicant or employee in decision making, it must give the individual written notice within ten days.25 In addition, anyone whose medical privacy rights have been violated has standing to bring an action for discrimination whether or not he/she has a condition that meets the definition of disability.26 This approach is far superior to the other state laws dealing with genetic discrimination. Unfortunately, a widespread lack of knowledge about the law among Minnesota employers and employees means that there has been little or no compliance with it.27

The last option is to enact laws similar to the state laws enacted already. Although this model seems to be favored currently, as reflected by the legislation pending in Congress28 and the states, it would merely perpetuate the status quo.

**CONCLUSION**

This review of insurance and employment demonstrates why it is so difficult to protect genetic privacy and confidentiality. Undoubtedly, procedural safeguards, such as strict application of informed consent and limits on disclosure by health care providers, are necessary. Nevertheless, clear substantive rights are also implicated by third-party access to and use of genetic information. What right do individuals have to health care? Is health insurance different from life insurance? What information does an employer legitimately need to have? These are only some of the questions that need to be answered.

The problem of genetic privacy and confidentiality cannot be solved by a single procedural law; resolution of the issues raises fundamental matters of equality of opportunity and allocation of resources. Only if we begin to understand the complexity and the difficulty of the challenge will we be able to develop comprehensive and thoughtful proposals to address genetic privacy and confidentiality.

**REFERENCES**


3. See id.

4. See, for example, G. J. Annas, L. H. Glantz, and P.A. Roche, The Genetic Privacy Act and Commentary (Boston: Boston University School of Public Health, 1995).


21. In Bragdon v. Abbott, 118 S. Ct. 2196 (1998), the U.S. Supreme Court, ruling 5–4, held that a dental patient with asymptomatic human immunodeficiency virus (HIV) was covered under the public accommodation (Title III) provision of the Americans with Disabilities Act (ADA). Of potential relevance to genetic discrimination cases, the Court held that, at least as to this plaintiff, HIV infection was a substantial limitation of the major life activity of procreation. A similar argument is likely to be raised by an individual with a genetic predisposition to illness. For further discussion of Bragdon v. Abbott, see W.E. Parmet, “The Supreme Court Confronts HIV: Reflections on Bragdon v. Abbott,” Journal of Law, Medicine & Ethics, 26 (1998): 225–40.


