
Genetic Exceptionalism and Legislative Pragmatism

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One of the most important and contentious policy issues surrounding genetics is whether genetic information should be treated separately from other medical information. The view that genetics raises distinct issues is what Thomas Murray labeled “genetic exceptionalism,” borrowing from the earlier term “HIV exceptional-ism.”¹ The issue of whether the use of genetic information should be addressed separately from other health information is not merely an academic concern, however. Since the Human Genome Project began in 1990, nearly every state has enacted legislation prohibiting genetic discrimination in health insurance; two-thirds of the states have enacted laws prohibiting genetic discrimination in employment, and other state laws have been enacted dealing with genetic discrimination in life insurance, genetic privacy, and genetic testing.² Bills in Congress also would prohibit genetic discrimination in health insurance and employment.³

Much has been written on the issue.⁴ Most commentators have cautioned against genetic exceptionalism, but to no avail.⁵ Legislators seem enamored of genetic-specific laws, and it is possible that they actually believe that genetic-specific laws are the best way to protect privacy and combat discrimination. Or perhaps they just think such laws are better than none at all, even though they recognize that the laws are flawed conceptually and in practice. Many legislators who hold the latter view undoubtedly have also concluded that more general laws dealing with such contentious issues as

access to health care and employment discrimination have little chance of being passed.

After considering the arguments in favor of and opposed to genetic exceptionalism, I argue in this article that genetic exceptionalism represents poor public policy. Because more desirable and far-reaching “generic” laws are often politically infeasible, legislators may still reasonably decide that it is better to enact a genetic-specific law than nothing at all. But there are only limited conditions in which that decision is reasonable.

The Policy Framework

New developments in genetic technology have increased our capacity to identify the source of biological specimens, determine familial associations, and predict the future health status of individuals. New genetic information also has raised a variety of novel issues in such diverse fields as family law, employment law, insurance law, and criminal law.⁶ When deciding on the legal response to this new information, policymakers have three main options: (1) maintain the status quo; (2) enact comprehensive, “generic” restrictions on the collection, use, and disclosure of health information; and (3) enact provisions for the special treatment of genetic information – the preferred option to date in the United States.

If genetic-specific laws are to be successful, three conditions must be met: (1) the term “genetic” must be defined clearly, logically, and with scientific precision; (2) there must be an efficient, low-cost way to separate genetic information from nongenetic information in health records; and (3) it must not only be possible to treat genetic information differently from other health information, but there must be a compelling reason to do so.

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Defining "Genetic"

From the standpoint of genetic privacy and genetic discrimination, *genetic* refers to predictive genetics. In determining the legal rights of individuals who are already affected with a physical or mental disorder, it is generally immaterial whether the disorder was caused by a germline mutation, a somatic mutation, environmental factors, a combination of factors, or something unknown. For example, there are two key issues in employment discrimination cases brought under the Americans with Disabilities Act (ADA): (1) Does the individual have a physical or mental impairment that constitutes a substantial limitation of a major life activity? and (2) Can the individual, with or without reasonable accommodation, perform the essential functions of the job safely and efficiently?⁷

The etiology of the impairment has no bearing on either determination. Thus, the issue of genetic discrimination arises when genetic factors indicate that a currently unaffected individual is at an increased risk of developing a physical or mental impairment at some point in the future.

To a large extent, the ethical and legal challenges associated with predictive genetics stem from two important time lags. One of these is the gap between the discovery of a genetic marker for an increased risk of illness and the development of therapies to prevent, treat, or cure the disorder. Thus, in the often-used example of Huntington's disease, scientists have identified the genetic mutation responsible for the condition, but there is still no medical intervention that will prevent or ameliorate it. The second time lag is the gap between a genetic test that indicates an individual has a genetic predisposition to a disease and the onset of symptoms. These time lags give rise to such ethical issues as whether children should be tested for adult-onset disorders (such as breast cancer) that cannot be prevented or treated in childhood,⁸ and whether young adults should be tested for late-onset disorders (such as Alzheimer's disease) that cannot be prevented or treated in adulthood.⁹ They also create economic incentives for commercial entities, such as employers and insurers, to consider the genetically increased risk that an asymptomatic individual will become symptomatic. If a cheap, effective intervention that would prevent or cure these conditions existed, then many of the social issues would disappear. In other words, the availability of a medical intervention would eliminate both time lags. Unfortunately, medical genetics has not yet advanced that far.

Even without medical breakthroughs in prevention or treatment, social policies may reduce or eliminate the economic risks of predictive genetic information. For example, in the United States, most individuals

with private health insurance obtain their coverage through employment-based group health insurance.¹⁰ The Health Insurance Portability and Accountability Act (HIPAA),¹¹ enacted in 1996, prohibits employer-sponsored group health plans from charging individuals higher rates or excluding certain medical conditions from coverage¹² based on an individual's current health or "genetic information."¹³ Thus, the only concerns about genetic discrimination in health insurance involve individual policies and nonemployer group plans to which HIPAA does not apply.

In the group health insurance market, the broad pooling of risks eliminates the issue of genetic discrimination for the vast majority of privately insured Americans, as well as all individuals covered under publicly financed health care systems such as Medicare and Medicaid. (This is why in countries with national health care systems, the issue of genetic discrimination is irrelevant to eligibility for health care.) At least for the moment, the political consensus for risk pooling does not extend beyond employment-based group health insurance to individual and nonemployer sponsored health insurance. Thus, in the absence of legislation prohibiting the practice, health insurers would be tempted to use genetic information to deny coverage to individuals who have a genetically increased risk of disease. Of equal or greater concern is the fact that many people who are at risk for genetic disorders and who might benefit medically or socially from genetic testing decline to undergo testing because of concerns about the effect it might have on their insurability.

The first step in devising a "genetic" solution to this "genetic" problem is to define "genetic." Many legislative and policy meetings have agonized over the definition. The narrow issue is sometimes cast as whether "genetic" should include only the results of a DNA-based test, or also tests for RNA, proteins, or other gene products. The real issue, however, is whether the definition should include family history, and it is on this point that attempts to define "genetic" usually falter. Definitions that fail to include genetic information derived from family histories are too narrow. For example, if a law prohibiting genetic discrimination did not include family history, it would not prohibit discrimination against an individual known to have a 50 percent risk of an autosomal dominant disorder (such as Huntington's disease) that had afflicted one of the individual's parents.¹⁴ On the other hand, definitions of genetic that include information derived from family histories are usually considered too broad.¹⁵ Family health histories often indicate an increased risk for common chronic disorders, which is why they are an essential element of clinical medicine. If family health history information were deemed genetic infor-

mation, then much “traditional” medical underwriting by insurers would become illegal.

As a scientific matter, the distinction between genetic and nongenetic disorders has become largely meaningless. Virtually all disorders have both a genetic and an environmental component.¹⁶ The respective influences of genes and environment may be strong or weak, but both are factors, and even when one appears to have a strong causal role in a disorder, the other may influence the disorder’s effect. Thus, even in single-gene disorders such as phenylketonuria, environmental influences like diet may determine the clinical outcome. Similarly, even in presumably environmentally caused illnesses such as infection, genetic factors may determine an individual’s sensitivity or resistance, as well as the effectiveness of various pharmaceutical interventions.

With “genetic” defined narrowly, so as to include only the results of a DNA-based test, and with health care providers keeping separate charts for the results of genetic tests, it might be possible to separate genetic and nongenetic medical information in a medical record. But because a narrow definition of genetic seems to leave the door open to some kinds of discrimination, it has not been widely accepted. In addition, keeping separate charts for genetic test results raises its own ethical problems. The primary reason for excluding genetic information is to deceive commercial entities that obtain the individual’s medical records pursuant to a signed authorization.¹⁷ Even though physicians are advocates of their patients, they should not misrepresent the contents of patients’ medical records. Consequently, the usual scenario is a broad definition of genetic and a single medical record.

Separating Genetic from Nongenetic Information

All of the state laws intended to bar genetic discrimination in employment prohibit employers from requiring that individuals take a genetic test as a condition of employment. Most of the laws also prohibit employers from requiring or requesting the results of genetic tests performed in the clinical setting. Some laws prohibit employers from requiring or requesting the disclosure of genetic information as a condition of employment, and “genetic information” could include family health histories. Virtually none of these laws, however, alters the right employers already have to require that conditional offerees sign an authorization for health care providers to disclose the individuals’ complete medical records, nongenetic as well as genetic, to the prospective employer or its designee.

As a practical matter, regardless of the wording of the state law, it is impractical or impossible to limit disclosure of health information to nongenetic infor-

mation. If a health care provider receives a patient’s authorization to release only nongenetic information to a third party, it is impossible to identify, isolate, and disclose only the nongenetic information. For example, at a hospital, health information from myriad sources and of various types is generally compiled in a single record that may reflect decades of health care rendered by dozens of health care providers. It would take a substantial amount of time and expense to identify which information in a voluminous record satisfied the statutory definition of “genetic” under a particular legislative enactment, and then to disclose only the nongenetic information. Consequently, even when such a law exists, providers faced with a request for limited but not easily segregated medical information (ability to do physical labor, for example) often simply release the entire record. Thus, even with laws prohibiting certain commercial entities from *using* genetic information, they can still *obtain* the information. Because genetic test results are widely accessible to employers and insurers, at-risk individuals are discouraged from undergoing genetic tests, thereby undermining an essential purpose of nondiscrimination laws.¹⁸

New information technology may allow for more targeted disclosures at a reasonable expense. For example, with an electronic health record divided into different data fields, it might be possible to release only certain types of health information. Nevertheless, health care providers are a long way from having such capabilities, and there is little indication that in designing new electronic health record systems, much if any thought has been given to making limited disclosures possible.¹⁹

Treating Genetic Information Differently

The third requirement for a successful genetic-specific law is a compelling reason to treat genetic information differently. As I have written elsewhere, there are seven main reasons cited by proponents to justify genetic-specific laws: (1) genetic information has implications not only for the individual but also for family members; (2) genetic information may have implications for reproduction and characteristics of future generations; (3) genetic information may be predictive; (4) genetic information often carries stigma, and the misuse of genetic information has led to eugenics, racism, and genocide; (5) genetic information is regarded as unique by the public; (6) there are other “special” categories of medical information for which separate protections have been adopted, including HIV/AIDS and mental illness; and (7) the political reality is that there is greater support for genetic nondiscrimination legislation than for more general and sweeping laws.²⁰

Although there is something to be said for each of these reasons, on reflection they are unpersuasive. The characteristics identified in the first three reasons are not unique to genetic information. For example, numerous socioeconomic variables (such as income level and insurance coverage) and medical factors (such as a family history of tuberculosis) also serve to predict the current and future health status of an individual. The problem of stigma and misuse – the fourth reason – does not call for the legislative responses proposed; public education and broad laws protecting the privacy of health information and prohibiting health discrimination would be more effective. The fifth reason is to some degree self-fulfilling: Genetic information is regarded as unique partly because genetic-specific legislation bolsters that view. And finally, genetic information is not analogous to existing “special” categories of medical information because that information – HIV/AIDS and mental illness – is much more easily isolated in a medical record. For example, HIV/AIDS is a discrete syndrome initially diagnosed by a single test, even though the manifestations vary. By contrast, genetic factors influence virtually all diseases, and genetic information may be based on family history or on the results of tests for thousands of different DNA markers.

That leaves reason number seven, the political issue. A variety of arguments have been offered against the enactment of genetic-specific nondiscrimination laws. One is simply that it is difficult to make a moral argument that discriminating against people on the basis of genetic information is impermissible, but that discriminating against them on the basis of other medical information is permissible. This argument, on which a literature already exists, I set to one side in this paper.²¹ Two other concerns have already been touched on above, namely, that there are intractable problems in defining “genetic” because the definitions are either too narrow or too broad, and that it is impossible to separate genetic information from other medical information in medical records. A fourth argument is that a general nondiscrimination law is easier to comply with than one restricted to genetic information. And fifth, by enacting general laws applicable to all forms of medical information, the stigma of genetic information will be diminished rather than reinforced.

It is likely that the passage of time will eliminate some of the pressure to regulate genetic information separately. Part of the stigma associated with genetic information stems from the fact that contemporary medical records (especially those maintained by primary care physicians) still rarely contain genetic information beyond family histories. As genetic test results and other genetic information become common in the

medical charts of numerous patients, at least some of the fear and sense of uniqueness associated with genetic information is likely to dissipate. Consequently, genetic information will be more widely considered indistinguishable from other medical information.

The Alternative to Genetic Exceptionalism

I have argued that genetic-specific laws have limited value in preventing or redressing harms caused by the uses and disclosures of genetic information. Genetic-specific laws also reinforce the stigma of genetic disorders (by treating them differently from nongenetic conditions) and ignore the underlying social problems that genetic privacy and discrimination exemplify. The fundamental issue raised by genetic discrimination in health insurance is the fairness of our system for allocating access to health care; the fundamental issue raised by genetic discrimination in employment is how to balance the rights of employers and employees in controlling access to employee health information and in deciding what role, if any, current or predictive health status should play in employment opportunities.

General legal standards are more effective in dealing with these problems than genetic-specific laws. As mentioned, genetic discrimination is not a concern for health care finance systems that are not based on individual medical underwriting. For example, genetic discrimination is irrelevant in government-sponsored programs (such as Medicare and Medicaid), and group-based health insurance. But individual underwriting in any insurance product is synonymous with “discrimination” (that is to say, with differentiation) since eligibility and rates are determined by risk classification. Thus, it will be virtually impossible to devise any effective measures to prevent genetic discrimination in a system based on “discrimination.”

The only logical conclusion is that, as a society, we need to decide if certain social opportunities raise such important social interests that universal access should be assured. If so, then a system should be devised to eliminate all risk classification. Perhaps all health insurance should be group-based, with mandatory participation and with various risk-spreading mechanisms. For other types of insurance, such as life insurance, we may decide that there is no fundamental right of access to the product and that individual underwriting is permissible, at least under some circumstances (perhaps for policies above a certain amount).

Many options have a chance of attaining one or more important social objectives in regulating genetic and other health information, but there is one option that is guaranteed to fail. We cannot hope to single out special underwriting or access to health information that

is ubiquitous and impossible to define, that cannot be feasibly segregated from other health information, and that cannot *logically* be treated specially. Unfortunately, our federal and state policies have embraced this principle, thereby promoting genetic over generic approaches to issues of access to and use of information by third parties.

With regard to employment, the common law permits employers to gather any information about applicants they deem relevant and to use any selection criteria not expressly prohibited by statute. Applicants usually have no choice but to acquiesce to employer demands for health information and must cede to the employers' decision of whether their current or likely future health is compatible with certain employment.

When Is Half a Loaf Better than Nothing?

Legislative champions for genetic-specific laws are easy to find, and they include sympathetic and persuasive advocates. Opponents are few, especially if the proposed legislation is narrow in scope. Only a small number of elected officials realize that genetic-specific laws are largely ineffective and may be counterproductive. To most lawmakers, it seems obvious that if there is a problem with genetic discrimination, then the solution is to enact legislation making genetic discrimination illegal.

More savvy lawmakers still may be reluctant to propose generic, rather than merely genetic, legislation, since generic legislation is extraordinarily difficult to enact.²² Support for logical, effective, and sweeping legislation is hard to find. The underlying issues – such as the right of access to health care, the relative rights of employers and employees to decide about health hazards in the workplace, and the principles to apply in medical underwriting for life and disability insurance – are extremely contentious. To date, efforts to address these issues have often been unsuccessful.

Because of the difficulty in enacting sweeping reforms, the policy question is whether it is a good idea to enact a genetic-specific law when there is insufficient support for broader legislation. In legislative circles it is often said that the perfect is the enemy of the good. In other words, many people would argue that it is better to have limited or even flawed protection against discrimination than no protection at all. On the other hand, enacting and then touting feel-good legislation with little or no substantive protection may lead the public to rely on the law to their detriment. It may also encourage people to believe in genetic exceptionalism, thereby making it a self-fulfilling prophesy, and it may erroneously convince legislators that they have resolved the underlying issues, thereby delaying enactment of meaningful legislation.

In my view, four conditions need to be met before it is appropriate to support a genetic-specific law as a fallback position to more sweeping legislation. First, there must be some value to the law, both in the sense that there is a demonstrated need for legislative action and that the proposed legislation will help to resolve one or more aspects of the problem. Second, the law must be drafted carefully to avoid unintended consequences, such as interfering with clinical care or medical research, or unreasonably interfering with the economic interests of third parties such as insurers or employers. Third, enacting the law must not serve to delay the enactment of legislation better designed to promote public policies, such as not coercing individuals into genetic testing and not dissuading at-risk individuals from being tested for fear of the social consequences. And fourth, both legislators and the public must realize that the law is not ideal but merely the best that can be achieved at the moment.

Many genetic-specific laws have failed to meet one or more of these four criteria. For example, several states have enacted laws providing that life insurance companies may use the results of genetic tests only if there is a sound actuarial basis for the action.²³ Every state, however, already has unfair trade practice laws that are applicable to life insurance and which require that, to be lawful, underwriting based on *any* test must be actuarially justified. The new laws thus appear to address the issue of genetics and life insurance but actually afford no new protections.

State laws that prohibit genetic discrimination in employment are another example. The number of reported instances (let alone legal cases) of genetic discrimination in employment is extremely small.²⁴ Nonetheless, concerns about employers' access to the results of genetic tests and possible discrimination have deterred some at-risk individuals from undergoing genetic testing.²⁵ Over 30 states have enacted genetic nondiscrimination laws, but only two states (California and Minnesota²⁶) have enacted laws that restrict employers' access to *any* non-job-related medical information.²⁷ Consequently, in all but two of the states that have enacted genetic nondiscrimination laws, employers may require, after a conditional offer of employment, that an individual sign a blanket authorization to release all of his or her medical records to the company. As a result, the laws permit employers to demand access to information they cannot legally use. Attempts to be more restrictive in access are impractical because, as noted earlier, there is no way as of yet to separate genetic from nongenetic information, especially when "genetic" is defined broadly, so as to include complex disorders and health histories. Therefore, without any meaningful limitations

on employers' access to genetic information, individuals will continue to be discouraged from undergoing genetic testing.

These are examples of laws without much value, and they have accomplished very little. Some other laws exemplify the problem of unintended consequences. Oregon enacted a law in 1999 designed to protect genetic privacy.²⁸ The law provided, among other things, that an individual's genetic information and DNA sample are the individual's property except when the information or sample is used in anonymous research. As it turned out, the law interfered with research because it prohibited the use of banked tissue samples that had been routinely collected in medical procedures without getting additional consent. The Oregon Legislature repealed the law after only two years, replacing the "property" language with a provision stating that "an individual's genetic information and DNA sample are private and must be protected."

It is difficult to assess whether enacting a weak or ineffective law delays the enactment of more meaningful legislation. On the one hand, the initial enactment may be viewed as "a foot in the door" or the first step to stronger legislation. Since 1995, every state to enact a law establishing a DNA forensic database for use in law enforcement has amended its law to add more categories of offenders who are required to provide DNA samples.²⁹ This expansion reflects the continuing efforts of the law enforcement community and its legislative advocates to promote forensic DNA banks.

On the other hand, "legislative fatigue" is sometimes used to describe the notion that having enacted *something*, legislators are ready to move on to the next issue and have no interest in reconsidering a problem they thought was resolved. For example, few amendments have been made to the privacy and antidiscrimination laws enacted in the last decade, especially to extend the privacy protections for individuals. Whether genetic legislation will be a precursor to stronger legislation or yield to legislative fatigue will depend on whether powerful legislative champions are satisfied with the initial version of the law.

My fourth condition is that legislators and the public realize that a genetic-specific law is not ideal. Unfortunately, in the press conferences and self-congratulation that usually follow enactment of legislation affording protection against genetic discrimination, there is rarely any mention of the limitations of the new laws. Many people, including legislators, probably assume that the problem has been solved. Legislative sponsors and supporters would then view it as a sign of weakness or ineptitude to admit that the bill they advocated is flawed or ineffectual. If media descriptions of the new laws are based on press releases and interviews

with advocates of the legislation, then the gaps in protection are unlikely to be noted.

No Shortcuts

From a policy standpoint, studying the effect of genetics is especially valuable because it forces us to return to first principles. Who should have access to health care? In a health care system that relies heavily on optional, employer-sponsored group health insurance, on what basis should individual health insurance be underwritten and priced? What is the role of private disability insurance in a system that uses both public and private sources to replace the incomes of those who are medically unable to work? What is the social purpose of life insurance and on what basis should the risk of mortality be shared by policyholders? What are the relative rights of employers and employees in making decisions about employees' fitness for duty and about the amount of employee health information that employers may reasonably obtain?

Genetic exceptionalism undercuts this essential reconsideration of the role of predictive health information in society. It allows elected officials to avoid difficult issues by enacting genetic-specific laws that seem to respond to a perceived new crisis, but in fact offer little or no protection and may even be counterproductive. It is not surprising that elected officials would want to avoid fundamental and controversial issues and focus instead on nominally protecting the public against the highly publicized evils of invidious genetic discrimination. For the time being, at least, it seems that the public is genetically predisposed to let them.

Acknowledgement

This article was originally published in the *Hastings Center Report* 35, no. 4 (2005): 27-33. Reprinted by permission. Research on the article was funded by the grant, "Genetics and Disability Insurance: Ethics, Law & Policy," NIH/5RO1-HG02089, Jeffrey Kahn and Susan Wolf principal investigators.

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