

The Human Genome Project in College Curriculum

Ethical Issues and Practical Strategies



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editors

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To the dedicated teacher-scholars who manage to take the complex issues that emerge in bioethics and make them understandable, relevant, and meaningful. And to the emerging teacher-scholars who will face an unlimited number of new bioethical challenges, especially Emily.

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Genetic Discrimination in Health Insurance

An Ethical and Economic Analysis



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1. Hopes and Fears Aroused by Genetic Testing

In the 1997 movie *Gattaca*,¹ DNA is destiny. Practically instantaneous analyses of individuals' entire genomes reveal their bearers' precise propensities toward heart disease, depression, nearsightedness, and a host of other major and minor physical and mental conditions. In the opening minutes of the film, on-screen text sets the events in the "not-too-distant future," but few who saw the movie upon its release would have predicted the advances in genetic testing that would be made in the ensuing decade. To be sure, the world of *Gattaca* remains distant, and has grown at least a little more illusory: Currently we have genetic tests for only a small fraction of the diseases and other conditions that appear to be hereditary, and we know too much about the pervasiveness of gene-environment interactions, in the production of individuals' phenotypes, to countenance any strong form of genetic determinism for most significant ailments.² Nevertheless, correlations between genes and diseases are being discovered at an impressive rate, making genetic testing one of the fastest growing areas of health care.

Genetic testing has obvious benefits. For example, Ashkenazi Jewish women who test positive for a mutation in the *BRCA1* or *BRCA2* tumor-suppressor gene have a lifetime breast cancer incidence of 82 percent, compared to an incidence of less than 20 percent for the female population at large,³ and although negative results offer no assurance of remaining cancer free (since most cases of breast cancer appear to have other causes), positive results can lead to more vigilant screening, more effective

treatment, and the saving of lives. Similarly, a young man with a family history of Huntington's disease, and who has yet to experience the (normally mid-life) onset of the disease's debilitating symptoms, may feel that only a genetic test will enable him to make responsible decisions on such major questions as whether to have children and what kind of career to pursue. Admittedly, such foreknowledge, especially in the case of a disease that has no treatment or cure, is not always an unalloyed blessing, and some individuals choose ignorance rather than run the risk of being given what they would regard as a death sentence.⁴ But for many people, the explosion in genetic testing is a source of nearly priceless information.

Equally, though, the explosion in genetic testing arouses fears of discrimination—in employment; in health, life, and disability insurance; and more amorphously in the creation of a "genetic underclass." Indeed, it is said that these fears are the greatest source of public concern about the ongoing revolution in genetics.⁵ How widely genetic discrimination is being practiced, where it is legal, is unclear. As early as 1996, a study of the perceptions of members of genetic support groups found that 22 percent believed they had been victims of genetic discrimination in health insurance,⁶ while a later study suggested that such fears were largely unfounded.⁷ Despite disagreement about the extent of actually occurring genetic discrimination, a broad consensus has formed in opposition to such discrimination. Naturally, positions vary from "no amount of such discrimination is acceptable"⁸ to more nuanced views, but the general movement against genetic discrimination is unmistakable,⁹ and governments in Europe as well as North America have taken steps to prohibit various forms of it.¹⁰

Genetic discrimination is often treated as a single phenomenon, but it can arise in many different contexts, as noted earlier, and these different contexts present different issues. In this chapter, I focus on genetic discrimination in the context of health insurance, both because of the obvious importance of health care to quality of life and because of certain distinctive features of insurance as a product sold in a competitive market. The conventional view is that such discrimination is immoral and ought to be illegal. The prevalence of this view is understandable, given the widespread belief, which I endorse, that every individual in a society as affluent as ours has a basic right to affordable health care. But prohibiting genetic discrimination in health insurance is not an effective way to protect this right. On the contrary, I argue here that because of the nature of health insurance, such a prohibition is misguided, and that its worthy aims must, instead, be pursued through reforms in our country's system of publicly provided health care.

2. *Fairness in the Marketplace*

Much of the opposition to genetic discrimination in health insurance stems from the belief that such discrimination would be unfair. There are several arguments for this claim, and while several of the most prominent ones may initially seem intuitively plausible, careful scrutiny shows them to have significant shortcomings. Furthermore, a *prima facie* case can be offered in support of the claim that it would actually be unfair to prohibit health insurers from differentiating among prospective customers on the basis of their genes.

No doubt the most prominent argument for regarding genetic discrimination in health insurance as unfair is that people cannot control the genes they are born with, and it is unfair for people to be disadvantaged (in having to pay more for health insurance, for example) due to factors beyond their control. But these claims, though plausible, do not imply that it is unfair for insurers to set higher than average premiums for people whose genes indicate that they will probably have greater than average health care needs. To see this, bracket the idea of health insurance for a moment and imagine a small-town doctor, Dr. Smith, who has a few hundred patients who pay her directly rather than having health insurance. Some of her patients, due to factors beyond their control, need more health care than others. Since Dr. Smith charges her patients in accordance with the goods and services they consume, these unhealthy patients have to pay more, to maintain their well-being, than her other patients do. Thus, they are disadvantaged (in having to pay more to maintain their well-being) due to factors beyond their control. But is it unfair of Dr. Smith to charge her unhealthy patients more? This does not seem to follow. Instead, it seems more reasonable to locate the unfairness in the failure of the community at large to bear the cost of the extra health care that its unfortunate members need. Analogous reasoning can, and should, apply to the case of health insurance: It is not unfair for insurers to set higher prices for people they predict will require more health care; rather, it is unfair that society at large does not bear more of these extra, and undeserved, burdens. I take up this point again in section 4.

A second argument for the unfairness of genetic discrimination in health insurance challenges the analogy between health insurance and the case of Dr. Smith by claiming that insurance is different from a fee-for-service business such as the medical practice in which Dr. Smith is engaged. Specifically, it claims that insurance is inherently a form of risk sharing,

in which the fates of the lucky and the unlucky are bound together and borne by all equally.¹¹ Admittedly, there is a grain of truth in this view of insurance, in the sense that no insurer could remain solvent if its lucky customers (those who do not end up needing much insurance) do not pay premiums sufficient to cover the extra claims of its unlucky customers (those who end up needing a lot of insurance).¹² But the idea of risk sharing does not show any unfairness in the setting of higher premiums for people with greater expected insurance needs. To see this, imagine that Dr. Smith offers her patients the following option: Instead of paying her on a fee-for-service basis, each patient can ask her to specify a monthly premium that they can pay instead. (Some patients might prefer the predictable monthly payment to paying on a fee-for-service basis, even if the premiums cost them more in the long run.) Dr. Smith, obviously, is now selling not only health care, as before, but also health insurance, with herself as the provider, to those patients who prefer that mode of paying for their health care. Is it unfair for her to set different premiums for different patients, depending on her predictions of their future health care needs? The idea of risk-sharing does not seem to give us reason to think so. Of course, in order for Dr. Smith's insurance option not to be a net loss for her, the premiums of her patients who end up needing less health care than she anticipates must be sufficient to cover the extra expenses of her patients who end up needing more health care than she anticipates. To this extent, Dr. Smith's patients who buy insurance are involved in risk sharing with one another. But the idea of risk sharing does not show that it is unfair for her to set different premiums for different people, depending on their predicted future health care needs.

A third argument purporting to establish the unfairness of genetic discrimination in health insurance invokes the fact that such discrimination typically involves setting higher premiums for customers because of the anticipated onset of conditions for which they are currently asymptomatic. Proponents of this argument claim that it is one thing to set higher premiums for customers with preexisting conditions (as is now standard practice), but that it is quite another to set higher premiums for customers with nonexistent, merely anticipated, conditions.¹³ The comparison with preexisting conditions, however, does not undermine, but actually bolsters, the case for taking customers' genes into account in the setting of premiums. The rationale for setting higher premiums for customers with preexisting conditions is simply that they are likely to have greater than average health care needs in the future, and premiums should be proportional to anticipated needs. As a result, any source of information

facilitating predictions of a prospective customer's future health care needs is as appropriate to consider as any other. If a customer is likely to have greater than average health care needs in the future, it is irrelevant whether this information is derived from genetic testing as opposed to a preexisting condition.

A final argument alleging the unfairness of genetic discrimination in health insurance is based on the fact that since genetic testing is still a relatively new field, and since the results of genetic tests are liable to be misunderstood by insurance underwriters, some customers' genetic predispositions to various diseases may be overestimated and their premiums set higher than they should be.¹⁴ This argument, however, assumes that it is unfair for a prospective customer to be quoted a premium that has been inflated by an error on the part of the insurer. But is this assumption true? If an insurer overestimates the future health care needs of a prospective customer who smokes, or who has a preexisting condition, and sets a higher than appropriate premium as a result, we don't accuse the insurer of treating the customer unfairly; instead, we note that the insurer is opening itself up to losing some of its customers—all of the ones whom it is overcharging—to insurers that estimate future health care needs more accurately. The situation is analogous to one in which a mechanic overestimates the work that will be required to fix my car and quotes me a higher price than he would if he estimated the scope of the job accurately. It may be inconvenient for me that the mechanic quotes me a price based on a miscalculation—I may have to keep shopping around, or I may pay the higher price because I don't know any better—but it isn't a case of unfairness.

So there are significant shortcomings in the main arguments for the unfairness of genetic discrimination in health insurance. Moreover, a *prima facie* case can be offered in support of the claim that it would actually be unfair to prohibit insurers from differentiating among prospective customers on the basis of their genes. It is a basic tenet of free markets that actors in such markets, be they individuals or firms, are free to enter into those commercial transactions they believe to be advantageous, and to decline to enter into those they believe to be disadvantageous. Implicit in this freedom is the right of actors to set different terms for their interactions with different other actors, and to gather and act on whatever information they deem relevant to their decisions. For example, workers are free to sell their labor at different rates to different employers, based on their predictions of the pros and cons of different jobs, and information-technology firms are free to quote different prices for setting up and maintaining different

clients' systems, based on their predictions of the different needs of those different clients. Fairness would require that insurers be free to quote different premiums for different customers, based on their predictions of the different needs of those different customers.

Admittedly, this line of reasoning establishes only a *prima facie* case in support of the claim that it would be unfair to allow insurers to take customers' genes into account in the setting of premiums. This is because, in my view, the free market is morally justified only insofar it produces benefits such as individual happiness (in the form of freedom of occupation, for example) and greater prosperity for society (by the workings Adam Smith likened to those of an invisible hand). Indeed, it seems very unpromising to set such consequentialist considerations aside and argue that any individual or firm has a natural right to freedom as extensive as that of actors in a free market; such rights, construed as natural rights, are more often assumed than given sound justifications.¹⁵ And if such consequentialist considerations (rather than, e.g., natural-law ones) are the basis for any moral justification that can be given for the free market, then it is not unfair to place restrictions on actors' freedom when there is more to be gained from such restrictions than from the continued unfettered operation of the invisible hand. In principle, then, it would be possible to argue that it would not be unfair to prohibit insurers from taking customers' genes into account in the setting of premiums, if it could be argued that the consequences for society would be sufficiently desirable. In the next section, however, I argue that such a prohibition can actually be expected to have undesirable social consequences.

3. Adverse Selection and Unintended Consequences

Prohibiting genetic discrimination in health insurance would further impair the already troubled health care system in the United States by artificially compromising the one essential conditions for a well-functioning insurance market, namely, approximate symmetry of information between insurers and insureds. How an informational asymmetry would arise from such a prohibition is obvious: If genetic discrimination in health insurance is prohibited, then while individuals will be able to use genetic testing to gain tremendous amounts of information about their future health care needs, insurers will not have, or (which comes to the same thing) will be required to proceed as if they did not have, that same information. How such an informational asymmetry would threaten the operation of the

health-insurance market is a complicated matter that can best be explored through a thought experiment involving a simpler kind of insurance than health insurance, such as term life insurance.¹⁶

Imagine a company called Yearly Life Insurance (YLI) that sells only one product: a life-insurance policy that takes effect on the day you purchase it, pays your beneficiary \$1,000,000 if you die within a year, and expires otherwise. The price you pay depends solely on your age on the day you purchase the policy, and although you can renew your policy to ensure uninterrupted coverage, you have to pay a slightly higher premium upon each renewal, in accordance with your slightly increased risk of death with each passing year. YLI has thousands of customers, from teens to centenarians.

Now suppose that, due to new legislation, life-insurances companies are prohibited from discriminating on the basis of age. YLI responds by setting its single premium for every customer at the average of the premiums that its customers had been paying, so that its annual revenue remains the same after the law as before. Suppose that this new rate for everyone is \$150, and that this happens to be what YLI had been charging sixty-two-year-olds when its premiums were based on customers' ages. Then YLI's product is suddenly a lot more attractively priced for people older than sixty-two, and a lot more unattractively priced for people younger than sixty-two. As a result, YLI gains older customers, and loses younger ones.

This, however, raises YLI's annual expenses, since older customers die more frequently than younger ones do. To stay solvent, YLI raises its premiums; the new price happens to be what YLI had been charging sixty-six-year-olds before the law took effect. At the new price, YLI's product will be too expensive for some customers, and the non-renewing customers will be disproportionately drawn from the younger ranks of YLI's customer base (since insurance appropriately priced for sixty-six-year-olds will remain a relatively good deal for customers in their seventies and eighties and so on). Again, to stay solvent while serving an older customer base, YLI raises its premiums, this time to the price it had been charging seventy-year-olds before the law took effect. Again, YLI loses younger customers and has to set its premiums higher still. After a few iterations of this cycle, YLI's extremely high premiums have cost it all but its oldest customers—the ones who had been paying such high premiums in the first place. All its other customers have no life insurance at all; they haven't fared any better with other companies, because other companies are going through

the same transformation. The result is extremely expensive insurance for extremely old people, and no insurance for anyone else.

Obviously the issue of prohibiting genetic discrimination in health insurance is much more complicated than this simple example: Health insurance provides benefits in varying amounts throughout one's life, not just in a fixed amount upon death; it is sold in more and less comprehensive policies, many other factors than genes are considered in the pricing of health insurance, and in the United States it is mainly provided through employers rather than being sold directly to individuals.¹⁷ Nevertheless, accounting for these complications leaves the story essentially unchanged when applied to health insurance in an age of genetic testing the results of which are kept hidden from insurers. Customers who anticipate relatively high health care expenses will find health insurance more of a bargain than those who anticipate relatively low health care expenses. As the former customers buy more insurance and the latter buy less, insurers will be forced to raise their premiums in order to stay solvent, leading to extremely expensive insurance for customers who anticipate extremely high health care expenses, and no insurance for anyone else.

This phenomenon, called adverse selection, is not merely a theoretical abstraction; its real-world importance was sufficient for the 2001 Nobel Prize in economics to be awarded to three economists "for their analyses of markets with asymmetric information."¹⁸ Moreover, it can arise not only in insurance, but in any market in which buyers and sellers are asymmetrically situated with regard to information relevant to their transactions. (One of the three Nobel Prize winners is most famous for an article about asymmetric information in a used-car market.¹⁹) Nevertheless, its relevance to insurance is particularly acute. When customers have information that insurers do not have, or are not allowed to act on in the setting of premiums, the market tends to evolve so that nearly all customers get priced out of it. Prohibiting genetic discrimination in health insurance would establish an informational asymmetry between customers and insurers, an asymmetry that would currently be significant and that would be likely to grow only more significant as genetic testing becomes more sophisticated and widely available to individuals wishing to make more-informed predictions about their future health care needs. It is ironic that the outcome that most advocates for a prohibition on genetic discrimination in health insurance are trying to prevent is one of decreased access to affordable health insurance, since that is precisely the outcome to which such a prohibition would tend to lead.

4. Toward Systemic Reform

I have argued that it is not unfair for insurers to distinguish among prospective customers on the basis of their genes, and it would not be socially desirable to prohibit insurers from doing so. On the contrary, such a prohibition would probably be counterproductive. Nevertheless, the goal of preventing decreased access to affordable health care is a worthy one, and if prohibiting genetic discrimination in health insurance will not achieve it, another means to it must be found. The obvious solution, in my view, is for the United States to institute a system of publicly funded basic health care for every resident, irrespective of genes and other indicators of future health care needs.²⁰

In advocating this solution to the problem of potentially diminished access to affordable health insurance in an age of genetic testing, I am obviously offering nothing novel; I mention my view on this topic only to locate my position vis-à-vis two other positions regarding health care and health insurance. Some proponents of prohibiting genetic discrimination in health insurance reject publicly funded universal basic health care; they favor preserving the present system and they see prohibiting genetic testing as a means to doing so. Obviously I disagree with proponents of this position about both the desirability and the feasibility of preserving the present system.²¹

Other proponents of prohibiting genetic discrimination in health insurance agree that it is imperative for the United States to adopt publicly funded universal basic health care; they and I just disagree on what should be done in the absence of that first-choice solution.²² But those who advocate prohibiting genetic discrimination in health insurance, but who agree that publicly funded universal basic health care is the real solution to this and many other problems, need to appreciate that by failing to acknowledge the probable consequences of prohibiting genetic discrimination in health insurance—namely, the problem of adverse selection discussed already—they are undermining the movement for the wholesale reform they agree is really needed. For they are implicitly suggesting that the present system, although imperfect, can be protected from the disruptions of genetic testing with the right kind of tweaking. In doing so, they overstate the promise of the present system and effectively lend support to those opponents of publicly funded universal basic health care who say that the stability and adaptability of the present system obviate the need for more thoroughgoing reform.

The ongoing revolution in genetics raises understandable fears about genetic discrimination. It is natural, when confronted with such a threat, to think of a prohibition as the way to stop it. Upon examination, however, such a prohibition does not possess either the moral warrant, or the economic rationale, that it might initially seem to have. Those who want to preserve broad access to affordable health care, and especially those who favor the adoption of publicly funded universal basic health care, should reject calls for a prohibition on genetic discrimination in health insurance.

Notes

1. *Gattaca*, written and directed by Andrew Niccol, released by Columbia Pictures (1997).
2. On this latter point, see Elliott Sober's appendix "The Meaning of Genetic Causation," in Allen Buchanan, Dan W. Brock, Norman Daniels, and Daniel Wikler, *From Chance to Choice: Genetics and Justice* (Cambridge: Cambridge University Press, 2000), pp. 347–370.
3. See Mary-Claire King, Joan H. Marks, and Jessica B. Mandell, "Breast and Ovarian Cancer Risks Due to Inherited Mutations in *BRCA1* and *BRCA2*," *Science* vol. 302 (October 24, 2003), pp. 643–646.
4. For nuanced discussion of this point, see Alice Wexler, *Mapping Fate: A Memoir of Family, Risk, and Genetic Research* (Berkeley: University of California Press, 1995).
5. See Buchanan et al. (cited in note 2), p. 27. See also Philip Kitcher, *Science, Truth, and Democracy* (Oxford: Oxford University Press, 2001), p. 184.
6. E. Virginia Lapham, Chahira Kozma, and Joan O. Weiss, "Genetic Discrimination: Perspectives of Consumers," *Science* vol. 274 (October 25, 1996), pp. 621–624.
7. Mark A. Hall and Stephen S. Rich, "Laws Restricting Health Insurers' Use of Genetic Information: Impact on Genetic Discrimination," *American Journal of Human Genetics* vol. 66 (2000), pp. 293–307.
8. Lisa N. Geller, "Current Developments in Genetic Discrimination," in Joseph S. Alper, Catherine Ard, Adrienne Asch, Jon Beckwith, Peter Conrad, and Lisa N. Geller, eds., *The Double-Edged Helix: Social Implications of Genetics in a Diverse Society* (Baltimore: Johns Hopkins University Press, 2002), pp. 267–285.
9. See, for example, Francis S. Collins and James D. Watson, "Genetic Discrimination: Time to Act," *Science* vol. 302 (October 31, 2003), p. 745.
10. Buchanan et al. (cited in note 2), p. 339.
11. In fact, Wisconsin's state-sponsored program for "Wisconsin residents who either are unable to find adequate health insurance coverage in the private market due to their medical conditions or who have lost their employer-sponsored group health insurance" is called the Wisconsin Health Insurance Risk Sharing Plan. See <http://www.dhfs.state.wi.us/hirsp/index.htm>, accessed on June 16, 2006.

12. Ironically (but fortunately from the point of view of social justice), the Wisconsin Health Insurance Risk Sharing Plan is only partially funded by actual risk sharing—i.e., policyholder premiums. In 2005, such premiums funded 57.9 percent of the program's costs of \$174.5 million, with the remainder being funded by legally compulsory "assessments paid by insurance companies writing health insurance policies in Wisconsin . . . and reduced payments to providers." See "Health Insurance Risk Sharing Plan: 2005 Annual Report" (http://www.dhfs.state.wi.us/hirsp/reports/annual_2005.pdf, accessed on June 16, 2006), pp. 1–2.

13. This argument is suggested by the proposal that insurers should be legally allowed to set higher premiums for customers with preexisting conditions, but prohibited from setting higher premiums for customers with merely anticipated conditions for which they are currently asymptomatic. This proposal is attributed to Henry Greely, and discussed approvingly, by Deborah Hellman in her "What Makes Genetic Discrimination Exceptional?," in Verna V. Gehring, ed., *Genetic Prospects: Essays on Biotechnology, Ethics, and Public Policy* (Lanham, Md.: Rowman & Littlefield, 2003), pp. 85–97. It should be noted that this proposal, as described by Hellman, concerns legislation and not fairness per se.

14. Karen H. Rothenberg and Sharon F. Terry, for example, write that "It is only reasonable to be concerned that health insurers and employers may not fully understand the implications and limitations of genetic test results and the complex relationships between genotype and phenotype." See their "Before It's Too Late—Addressing Fear of Genetic Information," *Science* vol. 294 (July 12, 2002), pp. 196–197.

15. See, for example, Robert Nozick, *Anarchy, State, and Utopia* (New York: Basic Books, 1974).

16. The threat of adverse selection resulting from prohibiting genetic discrimination in life insurance is briefly alluded to by William Nowlan in "A Rational View of Insurance and Genetic Discrimination," *Science* vol. 297 (July 12, 2002), pp. 195–196).

17. For more on the role of employers in providing health insurance for most Americans, and for a brief history of the events that (partly accidentally) brought about the present system, see Henry T. Greely, "Health Insurance, Employment Discrimination, and the Genetics Revolution," in Daniel J. Kevles and Leroy Hood, eds., *The Code of Codes: Scientific and Social Issues in the Human Genome Project* (Cambridge, Mass.: Harvard University Press, 1992), pp. 264–280).

18. See <http://nobelprize.org/economics/laureates/2001/index.html>, accessed on June 16, 2006. Adverse selection is discussed in most microeconomics textbooks and economics reference works.

19. George A. Akerlof, "The Market for 'Lemons': Quality Uncertainty and the Market Mechanism," *Quarterly Journal of Economics* vol. 84, no. 3 (August 1970), pp. 488–500.

20. Although the Wisconsin Health Insurance Risk Sharing Plan (discussed earlier, in notes 11 and 12) is framed as an insurance program, the fact that the state funds more than 42 percent of its costs (by taxing health insurers selling policies in Wisconsin and requiring discounts from health care providers) makes this program a laudable step in the direction of the sort of solution I advocate.

21. An obvious defect of the present system, of course, is that it leaves more than one in seven Americans uninsured. See Carmen DeNavas-Walt, Bernadette D. Proctor, and Cheryl Hill Lee, *Income, Poverty, and Health Insurance Coverage in the United States: 2004* (an August 2005 report of the U.S. Census Bureau), p. 16.

22. See, for example, Philip Kitcher, *The Lives to Come: The Genetic Revolution and Human Possibilities* (New York: Simon & Schuster, 1996), pp. 132–139.