

eral population the costs of medical progress that benefits a few members of the population.

Out of pure self-interest, we should worry about shifting to sick people the costs of essential interventions. Because of the successes of modern medicine, most of us will survive our heart attack or cancer and go on to live with one or more chronic diseases. We will need some expensive drugs, devices, or procedures. At some point in our lives, we may all join that small pool of users of high-cost care. When we are sick and scared, we do not want to be preoccupied by the cost of treatments.

So what can be done besides bemoaning the limitations of our resources and the human condition? One approach is to get smarter about which drugs and interventions are covered and which patients really need them. We could decide that insurance should provide comprehensive coverage just for interventions

that really work, and physicians could support the guidelines instead of undermining them. In cases in which an intervention's effectiveness is indeterminate, we could require that patients receiving it be enrolled in clinical trials or registries that would enable us to identify the molecular and clinical profiles of patients who will benefit from them. And we could get tougher about applying that knowledge and avoid using these interventions in situations in which they are unlikely to help. Innovative payment models, such as providing payment only in cases in which a drug actually leads to clinical improvement, are also worth exploring.

Providers could agree that considering costs in treatment decisions does not violate the Hippocratic oath and that improved efficiency is a core value of medicine today. We could strive to ensure that everyone receives effective treatment, rather than spending more and more on in-

effective interventions that end up not just wasting money, but also breeding resentment and conflict over who can afford to live and who cannot.

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1. Kolata G. Co-payments go way up for drugs with high prices. *New York Times*. April 14, 2008.
2. Miller K, Wang M, Gralow J, et al. Paclitaxel plus bevacizumab versus paclitaxel alone for metastatic breast cancer. *N Engl J Med* 2007;357:2666-76.
3. Romond EH, Perez EA, Bryant J, et al. Trastuzumab plus adjuvant chemotherapy for operable HER2-positive breast cancer. *N Engl J Med* 2005;353:1673-84.
4. Willey VJ, Pollack MF, Lednar WM, Yang WN, Kennedy C, Lawless G. Costs of severely ill members and specialty medication use in a commercially insured population. *Health Aff (Millwood)* 2008;27:824-34.
5. Emanuel EJ. The cost-coverage trade-off: "it's health care costs, stupid." *JAMA* 2008; 299:947-9.

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## The Genetic Information Nondiscrimination Act — A Half-Step toward Risk Sharing

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Consider three Americans — one with an increased genetic risk for colon cancer, one with a family history of colon cancer, and one with a colonoscopic finding of several large adenomatous polyps. Under the Genetic Information Nondiscrimination Act (GINA), which was recently signed into law by President George W. Bush, health insurance companies may not refuse to cover and may not raise premiums for the first two people, whose

genetic information or family history puts them at higher risk for colon cancer.<sup>1</sup> Insurers could, however, refuse to sell the third person an individual policy or could quadruple his or her premiums. If the third person is enrolled in an employer-sponsored group health plan, insurers could raise the rates for everyone in the group.

In making such distinctions, GINA is emblematic of this country's piecemeal and inconsistent approach to health care

policy, which makes little sense and leaves many Americans without access to care or in danger of financial ruin if they seek care. Our recent history is replete with examples of similar half-measures in health policy. The Emergency Medical Treatment and Active Labor Act (EMTALA) of 1986 ensures that neither the poor nor the sick can be denied emergency medical treatment, but it leaves those without insurance completely on their own when it comes to fol-

low-up care. So when a patient presents at the emergency room with a myocardial infarction with ST-segment elevation, she will receive a lifesaving coronary-artery stent, but she may not be able to afford Plavix (clopidogrel) — which she must take to avert in-stent restenosis — and may not have access to follow-up care, which might enable her to modify her risk factors for heart disease. Medicare might help if the patient is 1 day past her 65th birthday, but not if she is 1 day shy of it. Medicaid might help if her income is lower than the qualifying threshold in her state, but not if she earns \$1 more.

GINA, heir to this tradition, is yet another expression of this inconsistent approach to policy. It indulges our egalitarian instinct by protecting people who have an elevated risk of illness as a consequence of their genes or their family history. The law requires that the cost of insuring them against the diseases for which they have heightened genetic risk be spread over a larger insurance pool, ultimately raising costs for those whose risks are low or unknown. The sharing of this risk is appropriate, since these people bear no personal responsibility for their genes. Their bad luck could have befallen any of us.

But GINA does not protect people with other immutable characteristics — such as a finding on a colonoscopy — that predispose them to illness, though they, too, are more expensive to insure than the average person. An insurance company can discriminate against these people in coverage and pricing because of

the increased risk they represent, yet they bear no more responsibility for their increased risk than people whose genes predispose them to illness. If we are willing to spread the costs associated with genetic risk across the pop-



ulation, why shouldn't we do the same for all health risks?

We could content ourselves with observing that politics is the art of the possible and that incremental change is better than no change at all, if it were not for the fact that this sort of half-measure may be hazardous to our collective health.

First, GINA not only fails to protect the person with colonic polyps; it actually leaves him worse off than he would otherwise be. Because insurance companies may no longer make use of clearly relevant information such as family history in their risk assessment, they will rely even more heavily on current health status when setting rates, even when it has only slight value in predicting future illness. In a post-GINA world, not only will the very sick have even more trouble obtaining affordable insurance, but so will the mostly well.

Second, while those who get bad news from genetic tests will rely on GINA to obtain health insurance at a subsidized rate, those whose genes put them at lower risk can opt out entirely or, more likely, purchase insurance with higher deductibles, greater cost sharing, and more exclusions. If the lower-risk portion of the population segregates itself into what is essentially a separate insurance pool, the goal of spreading the cost of genetic risk cannot be satisfied.

These problems illustrate a reality that we should have understood long ago: in the long run, haphazard health care reform sometimes creates new problems even while solving old ones. It may also leave our system unstable and unsustainable — and, more important, leave patients worse off.

One response would be to retreat from the egalitarian impulse of GINA and leave health insurance to market forces, as we do with consumer goods. Health insurance risk would be priced as accurately as technology permitted, and patients would pay their own expected medical costs in premiums. Everyone would have an incentive to stay as healthy as possible, and no one would have an incentive to avoid the risk pool. The costs of modern medicine, however, make this version of social Darwinism undesirable for all but the wealthiest among us. Most of the population would be one illness away from bankruptcy.<sup>2</sup>

The better solution is to fully embrace the basic ethic of GINA and admit that the law's distinction between genetic information and other immutable char-

acteristics is arbitrary. The irony of GINA is that its application in today's world is limited by our current knowledge of the genetic basis of disease. A person with colonic polyps may have a genetic predisposition to them that is not yet understood. Indeed, one can imagine a future in which most, if not all, diseases are known to have genetic causes or at least are made more likely by genetic susceptibilities. In such a world, the distinction between genetic information and other health information would collapse entirely.

The arbitrary nature of the categories GINA creates suggests that we should fully commit ourselves to the step that the legislation approaches but is too hesitant to take: the prohibition of medical underwriting — the rating and pricing of health insurance on the basis of any health information, not just genetic information. Health insurance premiums should be assessed on

the basis of a “community rate” and should be set the same for all people within a given age group — possibly with exceptions somehow made for risk factors that are deemed to be within each person's reasonable control.

Moreover, to ensure that the costs of bad health are shared equitably, all Americans would have to be in the same risk pool. This would mean enacting a health insurance mandate either for employers or, if health insurance could be made affordable, for individuals — and specifying a minimum set of benefits that everyone would be required to have. Given the growing disparity between the cost of modern medicine and the incomes of many Americans, enforcing such a mandate would be difficult. Even with income-based subsidies, an individual mandate could place an undue financial burden on many families. Nonetheless, bringing everyone into

the same risk pool is an important long-term goal.

With such reforms, GINA could become the first step toward a just and sustainable health insurance system. This approach would recognize that, because many of the most important determinants of health are beyond people's reasonable control, no one should have to bear the costs of health care alone.

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**A video interview with Francis Collins, director of the National Human Genome Research Institute, about GINA is available at [www.nejm.org](http://www.nejm.org).**

1. Pub. L. No. 110-233, 122 Stat. 881 (2008).
2. Himmelstein DU, Warren E, Thorne D, Woolhandler S. Illness and injury as contributors to bankruptcy. *Health Aff (Millwood)* 2005;Suppl Web Exclusives:W5-64–W5-73. (Also available at <http://content.healthaffairs.org/cgi/content/abstract/hlthaff.w5.63v1>.)

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