

Keeping the GINA in the bottle: Assessing the current need for genetic non-discrimination legislation in Canada

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Rapid advances in genetic science and technology have led to the wide availability of genetic testing for a broad range of conditions. Genetic testing companies have started to promote these tests aggressively, even though their predictive value is often in doubt. Some worry that insurers, employers, and financial institutions might introduce genetic testing or use information about an individual's genetic predisposition to deny access to specific services or to charge exorbitant rates to individuals in specific risk categories.

The Genetic Information Nondiscrimination Act (GINA)[1] adopted by US Congress aims at addressing this concern. When finally adopted in May 2008, observers rejoiced that “[a]t last, the United States has a federal law that protects consumers from discrimination by health insurers and employers on the basis of genetic information.”[2] GINA is the culmination of a long process which began in 1995 when federal law makers first introduced the legislation. In the interim more than 45 American states passed their own genetic nondiscrimination acts.[3]

Such a high level of legislative activity indicates a deep and abiding public concern about the issue of genetic discrimination. Yet, the same level of concern has yet to make its way north. Although a recent Canadian study reports on perceptions of genetic discrimination with regard to people at risk for Huntington's disease,[4] in general discussion of the issue in Canada has been limited and is focused primarily on discrimination in the context of life-insurance.[5] More significantly, there is no comparable legislation at either the federal or provincial levels. Does the absence of such legislation mean Canadian

consumers are at higher risk of genetic discrimination? Does Canada require similar legislation? Our answer is a qualified “no” on both counts.

Although there has been widespread concern in the U.S. about discrimination on the basis of genetic test results, there are few documented examples of its occurrence, and no evidence that genetic testing for employment or health insurance purposes is already common.[3,6] Greely[6] maintains that current market conditions are such that there is relatively little incentive for insurers to use genetic testing to discriminate. Before pursuing such a course an insurer would need to be reasonably confident that the financial benefits of introducing genetic testing to differentiate people would significantly outweigh its costs. The potential costs in terms of negative publicity, employee dissatisfaction, and litigation would be significant if it were demonstrated that an employer had used individual genetic test information to deny access to employment or coverage.

Clearly U.S. lawmakers were not convinced that market disincentives alone would protect U.S. consumers. Canadians appear less concerned about this issue, and there is currently little if any momentum in favour of GINA type legislation. But while market forces are no more protective in Canada than they are in the U.S., there is still little pressure to adopt similar legislation here. In order to appreciate why this issue has played out so differently on either side of the border it is important to understand some details about GINA.

First of all, GINA's purview is confined to health insurance and employment, and does not cover life, disability, or long-term-care insurance. GINA prohibits health insurers from requesting or requiring individuals to undergo genetic tests, and from using genetic information to determine eligibility for coverage or to set premiums. In a similar vein it prohibits employers from using genetic information to make employment decisions with regard to hiring, firing, job assignments, and so forth. "Genetic information" in this context includes not only information about an individual's own genetic tests, but also genetic tests of family members (up to and including fourth-degree relatives). GINA's notion of genetic information is expansive in that it prohibits employers and health insurers from asking questions about any manifestation of a disease or disorder in a family member.[2,7] Thus covered entities under GINA cannot ask potential clients or employees whether there is a family history of cystic fibrosis or Huntington's disease, whether they have ever been tested for breast cancer or colorectal cancer, or whether anyone in the family suffers from heart disease. However, GINA does not prohibit routine tests such as for blood count, cholesterol, and liver-function.[1,2]

GINA targets health insurers and employers specifically because the majority of Americans (around 60 %) receive their basic health insurance through employment. To be denied employment on the basis of a genetic predisposition could effectively preclude both an individual and his or her dependents from access to basic health care. Thus one reading of GINA is that it is a tacit admission on the part of U.S. legislators that health care is a public good that can't be entrusted to the vagaries of market forces alone; it is socialized medicine by other means. This explains both GINA's somewhat expansive

notion of genetic information on the one hand and the careful exclusion of life, disability and long-term care insurers from its remit on the other. Indeed, the reason a genetic discrimination statute made its way through Congress while general health care reform has been stalled for years, may have much to do with who feels most at risk of genetic discrimination. It is those who currently have access to health care and employment in the U.S. who are most likely to access genetic services. This segment of the population is clearly more vocal, better connected, and has likely more direct influence on the legislative process.[8,9] Thus under GINA people at genetic risk are protected, but others, particularly the 18% of uninsured Americans, continue to suffer discrimination.

Canada has long considered basic health care to be a public good, and all Canadian residents enjoy access to it. This is the main reason Canadians in general have demonstrated less anxiety about genetic discrimination than have our neighbours to the south; it is also the reason there is currently no urgent need for GINA type legislation focused on health insurance in Canada. That being said, the protections Canadians enjoy are contingent on the strength of our publicly funded health care system, and the continuing availability of a broad range of services. One key criticism of GINA is that it applies only to individuals who are asymptomatic and who have a genetic risk factor, but does not prohibit adverse action against conditions that are already manifest or against non-genetic risk factors. “The essence of genetic discrimination in health insurance,” says one commentator,[3] “has nothing to do with genetics, it involves health policy. The best way to resolve the problem would be to enact laws based on the principle that individuals who are sick or more likely to get sick (from whatever cause) are entitled to health

coverage without regard to their current health status or risk.” Another remarks that: “The law itself may be more an artifact of a fundamentally flawed health care system than a one-size-fits-all solution to the problem of genetic discrimination.”[9]

The adoption of GINA, the policy debate surrounding it, and the publicly acknowledged crisis in the U.S. health care system should be taken seriously in Canada. In the absence of adequate publicly funded health care where accessibility is on the basis of need rather than on the ability to pay, there is continual pressure to develop various legislative and regulatory initiatives to correct serious problems of inequitable access to health care. But such initiatives, as GINA shows, create their own inequities and challenges.

No one argues that the Canadian healthcare system is unflawed, but on the fundamental health policy question of whether to treat health care as a public or a private good Canada has got it right so far. Nevertheless there has been much discussion of late about the need to further privatize health care in Canada, and mounting concern about the erosion of various aspects of our public system.[10]

The relative strength of our health care system notwithstanding, there is still a need to evaluate whether Canadians enjoy adequate protection against other forms of genetic discrimination. Inappropriate use of genetic technology could affect at-risk individuals in other contexts, such as immigration, adoption, or with access to financial services. Life, disability, and additional health insurance could present other areas of concern.[11] Many European countries with health care systems comparable to Canada’s have implemented

rules to protect against genetic discrimination in these areas.[12] We need to assess the specific roles of these goods and services, the nature and extent of current protections in Canada, and whether additional restrictions should be imposed.

The current absence of genetic discrimination statutes should at this time not affect Canadian's access to core health care services. But to the extent that Canadians increase their reliance on other insurance schemes, they will increase their need for solid protection against discrimination, genetic and otherwise.[13] If Canadians hope to keep the GINA in the bottle they will need to repair and strengthen their public system rather than dismantling it and turning more of it over to the market. And they will need to pay special attention to other domains in which genetic discrimination might yet be a concern.

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