

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

DARYL PULLMAN, TRUDO LEMMENS

**Daryl Pullman**, PhD, is Professor of Medical Ethics in the Faculty of Medicine, Memorial University, St. John's, NL, Canada. **Trudo Lemmens**, LicJur, LL.M (bioethics), DCL, is Associate Professor in the faculties of Law and Medicine, University of Toronto, Toronto, Ont., Canada.

**Competing interests:** None declared.

**Funding source:** Daryl Pullman's research is funded through the Atlantic Medical Genetics and Genomics Initiative, a Genome Canada / Genome Atlantic project. Trudo Lemmens' research is funded by a Social Sciences and Humanities Research Council grant.

**Correspondence:** Daryl Pullman, PhD, Faculty of Medicine, Memorial University, St. John's, NL, Canada A1B 3V6; 709-777-6220; fax 709-777-7382; dpullman@mun.ca

Rapid advances in genetic science and technology have led to the wide availability of genetic testing for a broad range of conditions. The companies that develop and market genetic testing technologies have started to promote their products 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 insure individuals in specific risk categories.

The background to the adoption of the Genetic Information Nondiscrimination Act (GINA) in the United States has important lessons for Canada, especially in view of the increasing trend toward privatized services within the Canadian public health care system. When the US legislation was 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."<sup>1</sup> GINA is the culmination of a long process that began in 1995 when federal lawmakers first introduced the legislation. In the interim, more than 45 American states had passed their own genetic nondiscrimination laws.<sup>2</sup>

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 angst 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,<sup>3</sup> discussion of the general issue in Canada has been limited and is focused primarily on discrimination in the context of life insurance.<sup>4</sup> More significantly, there is no legislation comparable to GINA at either the federal or the provincial/territorial level in Canada. Does the absence of such legislation mean that Canadians are at higher risk of genetic discrimination than Americans? Does Canada require similar legislation?

## The US experience

Despite widespread concern in the United States about discrimination on the basis of genetic test results, there were few documented examples of its occurrence, and no evidence that genetic testing for employment or health insurance purposes was common.<sup>2,5</sup> Greely<sup>5</sup> maintains that market conditions were such that there was relatively little incentive for insurers to use genetic testing to discriminate. Before pursuing such a course, an insurer would need to be confident that the financial benefits of introducing genetic testing to differentiate people would significantly outweigh the costs. As for employers, the potential costs of negative publicity, employee dissatisfaction, and resulting litigation would be significant if it were demonstrated that an employer had used an individual's genetic testing results as a basis to deny access to employment or to health insurance coverage.

Clearly, US lawmakers were unconvinced that market disincentives alone would protect consumers; thus the perceived triumph of GINA. Although market forces are no more protective in Canada than they are in the United States, Canadians appear to be less concerned about this issue than their neighbours to the south, and there is currently little pressure to adopt similar legislation in Canada. 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, GINA's purview is confined to health insurance and employment, and does not cover life insurance, disability insurance, 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). Indeed, 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.<sup>1,6</sup> 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 or colorectal cancer, or whether anyone in the family suffers from heart disease.<sup>1</sup>

GINA targets health insurers and employers specifically because the majority (around 60%) of Americans receive their basic health insurance through their employers. To be denied employment on the basis of a genetic predisposition could effectively preclude people and their dependents from access to basic health care coverage. Thus, one reading of GINA on its adoption in 2008 was that it was a tacit admission on the part of US legislators that health care is a public good that cannot be entrusted to the vagaries of market forces alone. 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 was stalled for years may have much to do with who feels most at risk of genetic discrimination. It was those who had access to health care and employment in the US who were most likely to access genetic services. This segment of the population is clearly more vocal, better connected, and more likely to exert a direct influence on the legislative process than those who are unemployed and without health insurance.<sup>7,8</sup>

### Lessons for Canada

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 their American neighbours; 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 their 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 vis-à-vis conditions that are already manifest or non-genetic risk factors. “The essence of genetic discrimination in health insurance,” says one commentator,<sup>2</sup> “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, “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.”<sup>8</sup>

The current health care reform initiative in the United States will certainly address part of this criticism.<sup>9</sup> (For general information about the US health reform program, see <http://www.healthreform.gov/>.) It will improve access to health insurance, for example, by offering tax credits for insurance premiums based on income and by prohibiting insurers from denying coverage because of pre-existing conditions or risk factors. To some degree, this could offer to those with any form of health risk what GINA offers only to those at genetic risk. It remains to be seen, however, to what extent overall access to health care will be improved and how important the additional protection offered by GINA will remain.

The adoption of GINA and the policy debate surrounding it in the US health care system should be taken seriously in Canada. In the absence of an adequately funded public health care system in which accessibility is based on need rather than the ability to pay, there is continual pressure to develop various legislative and regulatory initiatives to correct serious inequities in access to health care. But such initiatives, as GINA shows, create their own inequities and challenges.

No one argues that the Canadian health care system is without flaws, 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 the Canadian public system.<sup>10</sup> Also, Canada’s health care system provides only limited coverage for pharmaceuticals, which leaves most funding for this growing health care expenditure to private insurance.<sup>11</sup> Given the demonstrated market failures of the US health care system,<sup>12,13</sup> and the associated vulnerability of all citizens to potential genetic discrimination, it is especially important that Canadians think carefully about how to ensure equitable access to the full

spectrum of essential health care services in the face of continuing pressure to privatize greater portions of what is currently covered in the public system.

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 access to financial services. Life, disability, and additional health insurance could present other areas of concern.<sup>14</sup> Many European countries with health care systems comparable to Canada's have implemented rules to protect against genetic discrimination in these areas.<sup>15</sup> We need to assess the specific roles of these goods and services, the nature and extent of current protections in Canada, and the need—if any—to impose additional restrictions. Extensive academic debate on the issue of genetic discrimination in Canada has yielded various suggestions for further regulatory and legislative interventions.<sup>14,16</sup> Health policy scholars, patient advocacy groups, ethicists, medical researchers, the insurance industry, and other interested parties have raised specific issues, such as genetic discrimination in life insurance.<sup>17</sup> However, it may be time to move from discussion to action.

Our view is that genetic discrimination statutes focused exclusively on health insurance are not needed in Canada at this time. But, to the extent that Canadians find it necessary to increase their individual reliance on other insurance schemes for essential health care, they will simultaneously increase their need for solid protection against discrimination, genetic or otherwise.<sup>18</sup> If Canadians hope to keep the GINA in the bottle, they will need to repair and strengthen their public health care system rather than converting even more existing services from the public to private responsibility.

---

**Contributors:** Both authors contributed equally to the preparation of this article.

---

## REFERENCES

- Hudson KL, Holohan MK, Collins FS. Keeping pace with the times—the Genetic Nondiscrimination Act of 2008. *N Engl J Med* 2008;358(25):2661–2663.
- Rothstein MA. Putting the Genetic Information Nondiscrimination Act in context. *Genet Med* 2008;10(9):655–656.
- Bombard Y, Veenstra G, Friedman JM, Creighton S, Currie L, Paulsen JS, et al. Perceptions of genetic discrimination among people at risk for Huntington's disease: a cross sectional survey. *BMJ* 2009;338:b2175.
- Knoppers BM, Joly Y; Canadian Genetics and Life Insurance Task Force. Physicians, genetics and life insurance. *CMAJ* 2004;170(9):1421–1423.
- Greely HT. Banning genetic discrimination. *N Engl J Med* 2005;353(9):865–867.
- Abiola S. Recent developments in health law. The Genetic Information Nondiscrimination Act of 2008: "First major Civil Rights bill of the century" bars misuse of genetic test results. *J Law Med Ethics* 2008;36(4):856–860.
- Lemmens T. Selective justice, genetic discrimination, and insurance: should we single out genes in our laws? *McGill Law J* 2000;45(2):347–412.
- Erwin C. Legal update: living with the Genetic Information Nondiscrimination Act. *Genet Med* 2008;10(12):869–873.
- Iglehart JK. Historic Passage—Reform At Last. *N Engl J Med* 2010;362(14):e48.
- Flood CM, Roach K, Sossin L, editors. *Access to Care, Access to Justice: The Legal Debate over Private Health Insurance in Canada*. Toronto: University of Toronto Press; 2005.
- Blomqvist A, Xu J. *Pharmacare in Canada: Issues and Options*. Health Canada Working Paper Series (Working Paper 01-01). September 2001. Available: [http://www.hc-sc.gc.ca/sr-sr/alt\\_formats/hpb-dgps/pdf/pubs/hpr-rps/wp-dt/2001-0101-pharma-med/2001-0101-pharma-med-eng.pdf](http://www.hc-sc.gc.ca/sr-sr/alt_formats/hpb-dgps/pdf/pubs/hpr-rps/wp-dt/2001-0101-pharma-med/2001-0101-pharma-med-eng.pdf)
- Kuttner R. Market-based failure—a second opinion on U.S. health care costs. *NEJM* 2008;358(6):549–551.
- Kamerow D. Yankee Doodling. Our perfectly designed US health-care system. *BMJ* 2008;337:a2702.
- Lemmens T, Lacroix M, Mykitiuk R. *Reading the future? Legal and Ethical Challenges of Predictive Genetic Testing*. Cowansville: Les Éditions Thémis; 2007.
- Van Hoyweghen I, Horstman K. European practices of genetic information and insurance: lessons for the Genetic Information Nondiscrimination Act. *JAMA* 2008;300(3):326–327.
- Ontario Law Reform Commission. *Report on genetic testing*. Toronto: The Commission; 1996.
- Knoppers BM, Lemmens T, Godard B, Joly Y, Avar D, Clark T, et al. Genetics and life insurance in Canada: points to consider. *CMAJ* 2004;170(9):Online-1–Online-3.
- Lemmens T. Genetics and insurance discrimination: comparative legislative, regulatory and policy developments and Canadian options. *Health Law J* 2003;Special Supplement:41–86.

---

**Citation:** Pullman D, Lemmens T. Keeping the GINA in the bottle: assessing the current need for genetic non-discrimination legislation in Canada. *Open Med* 2010;4(2):95-97.

**Published:** 13 April 2010

**Copyright:** *Open Medicine* applies the Creative Commons Attribution Share Alike License, which means that authors retain copyright of their work and that anyone is able to freely copy, distribute, transmit or adapt the work as long as all adapted or derivative work is distributed under the same or similar licence to this one and all derivative or non-derivative work is attributed to the author and to *Open Medicine* as specified by the author or *Open Medicine* but in no way that suggests that the author or *Open Medicine* endorses the work or how it is used. Any of these conditions can be waived with permission from the copyright holder. These conditions do not negate or supersede fair use laws in any country. For more information, please see our Creative Commons Attribution ShareAlike 2.5 Canada Licence.

---