



LIBRARY of PARLIAMENT
BIBLIOTHÈQUE du PARLEMENT

BACKGROUND PAPER



Genetic Discrimination and Canadian Law

Publication No. 2014-90-E
16 September 2014

Julian Walker

Legal and Social Affairs Division
Parliamentary Information and Research Service

Library of Parliament ***Background Papers*** provide in-depth studies of policy issues. They feature historical background, current information and references, and many anticipate the emergence of the issues they examine. They are prepared by the Parliamentary Information and Research Service, which carries out research for and provides information and analysis to parliamentarians and Senate and House of Commons committees and parliamentary associations in an objective, impartial manner.

© Library of Parliament, Ottawa, Canada, 2014

Genetic Discrimination and Canadian Law
(Background Paper)

Publication No. 2014-90-E

Ce document est également publié en français.

CONTENTS

1	INTRODUCTION.....	1
2	INTERNATIONAL PERSPECTIVES.....	2
2.1	Treaties	2
2.2	Foreign Legislation.....	3
2.2.1	France.....	3
2.2.2	United States	3
2.2.3	The United Kingdom.....	4
3	GENETIC DISCRIMINATION AND CANADIAN LAW	5
3.1	Human Rights Laws in Canada	5
3.2	Genetic Information and Canada's Privacy Protection Regime.....	7
3.3	Insurance Laws in Canada	9
4	CONCLUSION	10

GENETIC DISCRIMINATION AND CANADIAN LAW

1 INTRODUCTION

Genetic testing, which involves the analysis of a person's chromosomes, genes, or gene products (proteins) to identify the presence of specific traits, can have many benefits. It allows people to learn about their parentage and ancestral origins and is helping scientists to map prehistorical routes of human migration.¹ It can be used to diagnose genetic conditions (diagnostic testing) or to identify a predisposition to a genetic disease (predictive testing). This information can help people initiate appropriate treatment early and adopt lifestyles that will minimize the possible harm of a genetic condition. It can guide the selection of pharmacologic therapies and can identify patients who are candidates for gene therapy, which uses various techniques to replace, correct, suppress, or eliminate a mutated gene.²

The possibility of improving outcomes and cost-effectiveness by tailoring therapy to a patient's genetic profile has prompted government funding in the emerging field of "personalized medicine."³ Although, at present, relatively few tests for genetic conditions are widely recognized as reliable, and while a positive test result does not necessarily predict the onset or severity of an illness, it is expected that genetic testing will continue to open up new areas of medical knowledge and new options for treatment.⁴ New tests are being developed at a rapid pace – as of November 2014, over 24,000 tests for more than 5,000 conditions have been registered with US National Institutes of Health – and these will increasingly become available.⁵

Genetic information can, however, also be used to discriminate against someone. For example, a genetic test could reveal that a person who is otherwise in good health has a higher risk of one day requiring advanced health care or being unable to work because of an inherited condition. This information could affect how decisions are made in such matters as insurance and employment. If an applicant for insurance has a higher risk for a certain disease, then that applicant presents a higher risk to the insurer of having to make payments for health coverage or life insurance. This may affect the terms of any policy offered to the applicant. Similarly, an employer may be less willing to hire a job applicant who is genetically at high risk of developing an illness or genetic condition.

Although the long-term ethical and legal consequences of genetic testing for employment matters, insurance contracts, and preventive medicine and treatment are not yet fully known, cases of alleged genetic discrimination have been emerging in different parts of the world, prompting calls from concerned citizens for government action.⁶ Canadian media have reported incidents of insurance companies discriminating against applicants on the basis of their potential to be affected by inherited genetic conditions.⁷ Witnesses before the Standing Senate Committee on Human Rights testified that some medical patients are reporting experiences of genetic discrimination and some are declining genetic testing that could help with their treatment because they fear being discriminated against by insurance companies.⁸

Several national governments – for example, in the United States, Australia and a number of European countries – have taken legislative action to address genetic discrimination. While Canadian human rights laws, insurance laws and privacy laws do contain provisions that seek to minimize unjustifiable discrimination and prevent improper access to or use of personal information, at present no laws in Canada provide specific protection against genetic discrimination.

This paper first reviews international instruments and approaches used in other countries before examining the Canadian laws that are relevant to the topic of genetic discrimination.

2 INTERNATIONAL PERSPECTIVES

2.1 TREATIES

In the 1990s the Human Genome Project, a large-scale international scientific research effort,⁹ mapped the full sequence of human genes. As its discoveries were publicly announced, concerns mounted over the ethical and legal issues raised by genetic testing and genetic manipulation. This led to the passing of new laws, industry policies and international treaties in the decade that followed.

The United Nations Educational, Scientific and Cultural Organization (UNESCO) has advocated for all states to provide protection from discrimination based on genetic data or genetic characteristics. In 2003, it adopted the *Universal Declaration on the Human Genome and Human Rights*,¹⁰ which in addition to seeking to protect the human genome from improper manipulations that may endanger the identity and physical integrity of future generations, also intends to prevent genetic discrimination and any use of genetic information that would be contrary to human dignity and human rights. Similarly, UNESCO's 2012 *International Declaration on Human Genetic Data* sets out ethical principles that should govern the use of human genetic information and seeks to ensure that such information is:

not used for purposes that discriminate in a way that is intended to infringe, or has the effect of infringing human rights, fundamental freedoms or human dignity of an individual or for purposes that lead to the stigmatization of an individual, a family, a group or communities.¹¹

In Europe, most members of the Council of Europe have signed, if not yet ratified, the *Convention on Human Rights and Biomedicine*.¹² Signatory states¹³ are required to bring their laws into conformity with the principles of the Convention. Article 11 of the Convention generally prohibits “any form of discrimination against a person on grounds of his or her genetic heritage.”¹⁴

On 7 May 2008, the *Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Genetic Testing for Health Purposes* was adopted by the Committee of Ministers of the Council of Europe; this expands upon the Convention's provisions pertaining to genetic testing in order to define and safeguard the pertinent rights.¹⁵ To date, only a few states have signed and ratified the Protocol.¹⁶

2.2 FOREIGN LEGISLATION

Countries that have passed laws to address genetic discrimination have taken various approaches. One of these is to impose limitations on contractual liberties in employment or insurance.¹⁷ This may include adding general prohibitions to human rights legislation against discrimination on the basis of genetic characteristics¹⁸ or creating specific legal rules for insurance providers and employers. For instance, insurers and employers may be prohibited from requesting that a client or applicant undertake genetic testing or provide previous test results; or, they may simply be prohibited from using test results in making certain types of decisions that could discriminate adversely against a client or applicant (such as in the calculation of payments to an insured or the assignment of particular tasks to an employee).

Another approach to genetic discrimination has been to adopt more sophisticated privacy legislation to protect genetic data from being collected, used and disclosed without the consent of those involved, subject to certain exceptions. Some jurisdictions have developed laws to protect the rights of patients and to give them greater say over their health information, how it may be used, and in what context.¹⁹

2.2.1 FRANCE

After undertaking a review of its legislation in 1999, France made a number of amendments to various laws to ensure that they respect the general principle of non-discrimination with regard to genetic characteristics. Laws covering employment and labour,²⁰ health, criminal law and insurance,²¹ as well as general civil rights, were modified to tightly control the full process of genetic testing, from pre-contract testing through to the fulfilment of contractual obligations. These amendments represent a very restrictive approach, ensuring that no unauthorized genetic information can be used by insurance companies in dealing with their clients or by employers in hiring or retaining their employees. Although these amendments serve to broadly prohibit discrimination on the basis of genetic characteristics,²² they also stipulate that genetic tests may be taken only for valid medical or scientific purposes²³ and set out penalties for using genetic information for other purposes.²⁴ For instance, the *Penal Code* now states that the use of information about an individual that has been obtained by studying his or her genetic characteristics other than for medical purposes or scientific research is punishable with one year's imprisonment and a fine of €15,000.²⁵

2.2.2 UNITED STATES

The United States passed the *Genetic Information Nondiscrimination Act of 2008*²⁶ (GINA), which is limited to addressing genetic testing in the context of health insurance and employment. It does not cover life insurance, disability insurance or long-term care insurance.²⁷ It regulates when genetic testing may be done for research purposes; confirms that, for the purposes of this law, references to "genetic information of an individual" include a fetus or an embryo; amends a number of other pieces of federal U.S. legislation to prohibit a group health plan from adjusting premium or contribution amounts for a group on the basis of genetic information; imposes penalties for any contraventions of the Act; and permits individuals to make complaints against employers regarding discrimination.²⁸ GINA does prescribe certain situations in which genetic testing may be required or requested (such as "for genetic monitoring of

the biological effects of toxic substances in the workplace”), as well as how such information must be treated confidentially.²⁹

Ultimately, GINA prohibits employers, employment agencies and labour organizations from discriminating against individuals because of genetic information³⁰ and limiting or classifying them because of genetic information in any way that would adversely affect their status or deprive them of employment opportunities.

The GINA makes it clear that a health insurance issuer may not require a genetic test,³¹ impose a “preexisting condition exclusion on the basis of genetic information”³² in their insurance policies, or exclude any benefits based on such a pre-existing condition. It does not, however, preclude a group health insurance provider from obtaining or using the results of a genetic test in making a determination regarding payments after a claim; this appears to mean that the results of genetic testing may in fact be used to calculate the amount of the payments paid out to insured persons under a particular plan.³³ Only the minimum amount of information necessary to accomplish any intended purpose may be obtained, however.

2.2.3 THE UNITED KINGDOM

The United Kingdom has taken a non-legislative approach to genetic discrimination. In 2007, the government undertook a comprehensive review of its anti-discrimination laws and decided against adding any prohibitions against discriminating on the grounds of genetic characteristics.³⁴ Insurance providers and employers are legally responsible for handling genetic information in accordance with the *Data Protection Act 1998*,³⁵ which, similarly to Canada’s privacy laws discussed below, provides rules for the gathering and use of personal information.

The insurance industry in the United Kingdom has, however, voluntarily implemented a restrictive agreement on the use of genetic testing in certain circumstances since 2001. The basic terms of the *Concordat and Moratorium on Genetics and Insurance* adopted by the Association of British Insurers are that customers will neither be asked to, nor be put under any pressure to, undergo a predictive genetic test in order to obtain insurance or to disclose any predictive or diagnostic genetic test results acquired as part of clinical research or after the policy has started, whether their own test or that of another person (i.e., a blood relative).³⁶ Exceptions are made for certain situations, however. Customers may be required to disclose the results of predictive genetic tests for life insurance policies over £500,000, or critical illness insurance over £300,000, or for income protection insurance that pays annual benefits over £30,000. When the cumulative value of insurance exceeds these financial limits, insurers may seek information about, and customers must disclose, the results of tests approved by the Genetics and Insurance Committee³⁷ for use for a particular insurance product, subject to the restrictions in the Concordat.

Furthermore, insurers are permitted to seek, with customers’ consent, access to certain family medical history, diagnostic (but not predictive) genetic test results, and reports from general practitioners in order to accurately price the additional risk from any health problems an applicant discloses. An appeals mechanism has been devised for any disputes or complaints about how genetic information has been used by insurers.³⁸

3 GENETIC DISCRIMINATION AND CANADIAN LAW

No laws in Canada explicitly address genetic discrimination, and no court cases have directly examined the scope of any legal protection Canadians might have from genetic discrimination. However, basic rights contained in existing laws, and interpretations thereof, allow for some analysis of how any future cases of genetic discrimination might be handled.³⁹

In 2013 a team of academics reviewed the law relevant to genetic discrimination and concluded that, while no cases have as yet taken up this issue, this “does not suggest that” such discrimination does not take place.⁴⁰ The researchers found 468 tribunal and court decisions that examined a genetic predisposition as part of “describing the causal origins of health related conditions” in various areas of the law, including “criminal, family, workers’ compensation and tort.” For instance, in some cases, “genetic predisposition was used to argue whether the claimant’s condition was inherited rather than related to the workplace or the negligence of the defendant” or to “explain the origin of a mental health condition in addressing the issue of criminal responsibility.” The authors warned that the case law suggests that there is a “tendency to describe the underlying basis of health and disease as genetic,” and that this can downplay “the complexity of causal factors of disease” and the “social determinants of health and disability.” This conclusion is meant to caution policy-makers to consider that a tendency to place too much emphasis on genetic factors is a concerning consequence of genetic testing.

3.1 HUMAN RIGHTS LAWS IN CANADA

Discrimination in Canada is addressed primarily under federal, provincial and territorial human rights laws. As “human rights” are not explicitly listed under the enumerated heads of power in sections 91 and 92 of Canada’s Constitution,⁴¹ laws that address human rights concerns have been passed at the federal, provincial and territorial levels to respond to various matters within those jurisdictions.⁴² While there is some diversity among Canadian human rights laws, the principles and enforcement mechanisms are very similar from jurisdiction to jurisdiction.⁴³ Each statute prohibits discrimination on specified grounds, such as race, sex, age, religion, disability and, in the context of employment, accommodation and publicly available services. The *Canadian Human Rights Act* (CHRA) is the principal human rights statute in the federal sector.⁴⁴ It applies generally to federal government departments and agencies, Crown corporations, and federally regulated businesses.

The *Canadian Charter of Rights and Freedoms*, which forms part of Canada’s Constitution, also seeks to prevent discrimination. Section 15(1) guarantees that every “individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.”⁴⁵ The Supreme Court has concluded that this list of prohibited grounds of discrimination, also known as the “enumerated grounds,” is not exhaustive and has determined that there are “analogous grounds” that should also be considered as included. To date, these grounds are citizenship, sexual

orientation, marital status, and “Aboriginality-residence.”⁴⁶ The Court considers enumerated and analogous grounds to be personal characteristics that are “immutable, difficult to change, or changeable only at unacceptable personal cost.”⁴⁷

At present, it can only be speculated how Canadian courts might treat a case involving genetic discrimination, since, as noted above, there has yet to be a court or tribunal case that has directly answered the question of whether genetic characteristics constitute a prohibited ground of discrimination. If a case of genetic discrimination were to proceed before a court or tribunal, “genetic characteristics” could be put forward by a complainant for inclusion as an analogous ground. A court or tribunal could also potentially find that in such a case the grounds of “mental or physical disability” or “handicap” contained in human rights laws already apply for some genetic conditions.⁴⁸ Currently, the definition of disability in the CHRA defines “disability” only as “any previous or existing mental or physical disability and includes disfigurement and previous or existing dependence on alcohol or a drug.”

There are some precedents that would likely influence any court examining genetic discrimination. In the Supreme Court of Canada decision *Quebec (Commission des droits de la personne et des droits de la jeunesse) v. Montréal (City); Quebec (Commission des droits de la personne et des droits de la jeunesse) v. Boisbriand (City)*,⁴⁹ the Court examined complaints from three people who had been excluded from employment as a result of having been tested for medical conditions that had not in fact developed into any concrete physical ailments that might impede their ability to perform their duties. Two individuals had spinal anomalies and another had asymptomatic Crohn’s disease. Although it did not specifically address the issue of genetic discrimination, the Court determined that these genetic susceptibilities constituted a “handicap,” one of the enumerated grounds under the Quebec *Charter of Human Rights and Freedoms*.⁵⁰ It added that a broader definition of “handicap” was necessary to serve the purposes of the Charter, particularly given “the rapid advances in biomedical technology, and more specifically in genetics, as well as the fact that what is a handicap today may or may not be one tomorrow.” As noted by Trudo Lemmens, an expert in health law, “The conditions dealt with in this case show a great resemblance to genetic susceptibilities or predispositions: they were asymptomatic conditions that did not reveal any concrete immediate problem, but created concern in the employer of predisposition to increased risk of injury or disease.”⁵¹

Over the last 15 years, a number of proposals have been made to amend Canada’s human rights legislation to explicitly include genetic characteristics as a prohibited ground of discrimination at the federal level. In 2000, the Canadian Human Rights Act Review Panel, established by the federal Minister of Justice, recommended that the definition of “disability” in the Act should “be amended to include the predisposition to being disabled” in order to respond to concerns about genetic discrimination.⁵² In 2010, then Members of Parliament Judy Wasylycia-Leis and Bill Siksay introduced private members’ bills that proposed to amend the CHRA to add “genetic characteristics” to the list of prohibited grounds. Bills C-508 and C-536, both titled An Act to Amend the Canadian Human Rights Act (genetic characteristics), died on the Order Paper at the dissolution of the 40th Parliament.⁵³

More recently, private members' bills introduced in the 41st Parliament to address this issue have included bills C-445⁵⁴ and S-201,⁵⁵ introduced by Member of Parliament Libby Davies and Senator James S. Cowan respectively. Although both of these repeat the proposal to add "genetic characteristics" to the CHRA, Bill S-201 proposes other amendments. It would add new sections to the *Canada Labour Code*,⁵⁶ the main employment law within federal jurisdiction. These amendments would, among other things, protect an employee's right to not be required to take a genetic test or to disclose the results of a test already taken. It would prohibit employers from taking actions such as dismissing, penalizing or refusing to pay an employee as a consequence of the results of any genetic tests or because the employee refused to take a test or to disclose the results of one.⁵⁷

Bill S-201 also proposes criminal sanctions for actions such as when one person requires another to undergo a genetic test or disclose the results of one as a condition of "(a) providing goods or services to that individual; (b) entering into or continuing a contract or agreement with that individual; or (c) offering or continuing specific terms or conditions in a contract or agreement with that individual."⁵⁸ It creates an exception for insurance contracts that exceed \$1,000,000 or that pay a benefit of more than \$75,000 per annum. One reason for this is to ensure that individuals do not take out policies for excessively large amounts after learning that they are at a high risk of a genetic disease or condition.⁵⁹ In Ontario, Bill 127 seeks to add "genetic characteristics" to the province's *Human Rights Code* as a prohibited ground of discrimination.⁶⁰

Various organizations, legal experts and other commentators have argued in favour or against the need to pass legislation in Canada to explicitly address genetic discrimination.⁶¹

3.2 GENETIC INFORMATION AND CANADA'S PRIVACY PROTECTION REGIME

Canada's regime for regulating the private sector with respect to the collection, use and disclosure of an individual's private information, especially with respect to health, is complex. The federal *Personal Information Protection and Electronic Documents Act* (PIPEDA)⁶² governs the handling of personal information by the private sector in general, but it does not apply uniformly across the country. There are also various pieces of provincial legislation,⁶³ some of which regulate the handling of personal information by the private sector, and some of which regulate the handling of health information by any type of person or organization who acts as a custodian of it. Some of these laws replace PIPEDA within the province or operate in tandem with PIPEDA.⁶⁴ These laws can affect the amount and type of information insurance companies, employers or others may obtain, including doctors,⁶⁵ employers in the private or public sectors,⁶⁶ and public bodies involved in health care delivery.⁶⁷

An organization under the jurisdiction of PIPEDA must obtain the consent of an individual for the collection, use or disclosure of that individual's personal information⁶⁸ and must explain the purposes for the collection, use or disclosure to the individual in order to ensure this consent is meaningful.⁶⁹ Principles set out in PIPEDA state that companies covered by PIPEDA must "take into account the sensitivity of the information" in determining the form of consent to be used for its collection, use or

disclosure, and gives the example of “medical records” as information that is “almost always considered to be sensitive.”⁷⁰ The Schedule also recommends higher security safeguards for sensitive information.⁷¹ The Office of the Privacy Commissioner of Canada has indicated that any company subject to PIPEDA would need to be able to demonstrate that any genetic information sought would serve “a legitimate purpose” before its collection and use would be appropriate.⁷²

As PIPEDA does not include a definition of what constitutes genetic information, or any guidance on how it should be handled, there is still some question about whether genetic information is included in the standard definitions for private information on which much of this regulatory regime is based. In fact, most privacy laws were passed before widespread genetic testing capacities had been developed, and therefore do not contain specific language about genetic information.⁷³

A complicating factor for the regulation of the use of genetic data is that it can provide information not only about the individual tested but also about his or her family members. Tests that reveal an inherited predisposition to a particular disease in one person’s genes may thereby reveal that this predisposition exists in their relatives. This raises the issue of whether even express consent solely by the tested individual to the disclosure of any such personal information is sufficient to cover all parties to whom the information in the data might belong. Some scholars have proposed that genetic information should be conceived as “family property” or something that is owned jointly.⁷⁴ This particular characteristic of genetic information may make it more difficult, as time goes on, to incorporate it into the standard privacy model, which designates individuals as the owners of their own personal information to the greatest extent possible.

The Office of the Privacy Commissioner of Canada has identified a need for further national discussion on this issue and has commissioned papers from and engaged with leading experts on the topic.⁷⁵ In 2009, the Privacy Commissioner emphasized that protecting genetic information is a strategic priority that “will become increasingly important to all federal policy makers in the very near future.”⁷⁶ With respect to enforcement, if an insurer or employer breaches PIPEDA, then the individual whose personal information is affected can file a complaint with the federal Privacy Commissioner, who can investigate.⁷⁷ The federal Privacy Commissioner has made a number of investigative findings in response to complaints about the collection, use and disclosure of personal information by insurance companies.⁷⁸ Since the Commissioner is an ombudsperson, his findings and recommendations are not binding, but in practice companies do generally attempt to comply with them. If this is not sufficient to ensure compliance, an individual can apply for a hearing at the Federal Court on matters⁷⁹ that have been investigated by the Commissioner,⁸⁰ or the Commissioner can also apply to the Court for a hearing on behalf of the individual.⁸¹ The Court can order the company to comply with PIPEDA and award damages to the individual.⁸²

3.3 INSURANCE LAWS IN CANADA

Insurance contracts in Canada are generally governed by provincial laws. Although provincial human rights codes may already provide some protection for individuals from genetic discrimination, they also include some exceptions that may allow automobile, life, accident or sickness or disability insurance providers to make distinctions based on an applicant's age, sex, marital status, family status, or physical or mental disability.⁸³ A discriminatory practice in insurance may be justified on reasonable and bona fide grounds – in other words, if it is based on accepted and sound insurance practices and if no practical non-discriminatory alternative exists.⁸⁴

In accordance with Canada's Constitution, and judicial interpretation thereof, regulating the terms of an insurance contract is considered a matter of provincial jurisdiction.⁸⁵ For insurance companies who are federally incorporated,⁸⁶ the primary statute regulating their activities is the *Insurance Companies Act*.⁸⁷ Although the federal government plays a role in regulating the industry in Canada, that role is primarily limited to the oversight of banks and trust companies that offer insurance policies and services, and to the oversight of federally incorporated or registered insurance companies. One purpose for this is to ensure that these institutions and companies remain solvent and are in compliance with the statutes under which they are incorporated or registered and run. Although the federal legislature may use its trade and commerce power under section 91(2) of the *Constitution Act, 1867* to pass laws pertaining to insurance and other business contracts, or its powers to pass criminal laws under section 91(27), previous attempts to use this power to regulate the insurance industry have been largely unsuccessful.⁸⁸

Rules respecting the formation of insurance contracts and policies are regulated primarily by provincial laws. For example, Ontario's *Insurance Act*⁸⁹ sets out the general duty of an insurance applicant to disclose "every fact within the person's knowledge that is material to the insurance" pursuant to a medical examination. Currently, provincial laws do not contain provisions pertaining to genetic discrimination.

In the absence of any government regulations, the current position of the Canadian Life and Health Insurance Association Inc., the Canadian Institute of Actuaries, and the Canadian Life Insurance Medical Officers Association is that, while companies will not require genetic testing of applicants for insurance, they will ask whether the applicant has been genetically tested in the past, and they will require disclosure of those test results where they exist.⁹⁰ This position is generally justified on the basis that there exists a good faith obligation under most provincial laws for an insurance applicant to disclose to the insurance company all information that might have a bearing on the company's assessment of risk.⁹¹ These organizations have expressed concern that insured persons who learn, after taking a genetic test, that they are at high risk for a genetic disease could knowingly take out policies for large amounts of additional coverage without insurers being aware of any increased risk.⁹² Disclosing the results of genetic testing would therefore help ensure that both parties negotiating an insurance contract would have the same knowledge about the health risks of the applicant.

4 CONCLUSION

Genetic information and how we use it is already changing our world, our perspectives on human history and our approach to health matters. It is expected that further changes yet unimagined will emerge as genetic science is applied to more aspects of our lives. One significant change on the horizon is personalized medicine. If it can help people to obtain treatment specially tailored to their genetic profiles, thereby selecting the right medicine or the most appropriate therapies sooner and in a more cost-efficient manner, significant savings to the health care system could result.

Although arguments may be made for or against⁹³ new legislation to prevent genetic discrimination, it can be expected that Canadians will also need to feel comfortable in knowing that obtaining and sharing their genetic information will not have negative consequences. One of the reasons given by the U.S. government for the *Genetic Information Nondiscrimination Act* was

to help ease concerns about discrimination that might keep some people from getting genetic tests that could benefit their health. The law also enables people to take part in research studies without fear that their DNA information might be used against them in health insurance or the workplace.⁹⁴

Genetic testing is a potential Pandora's box, as it could be used for less than altruistic purposes. In the wrong hands, genetic science could be used to cause more harm than good. As genetic testing becomes more commonplace, Canadians will be challenged to determine the role they wish genetic information to play in their lives.

NOTES

1. See, for example, National Geographic, [The Genographic Project](#).
2. See, for example, The American Society of Gene & Cell Therapy, "[What is gene therapy?](#)" FAQs.
3. See, for example, Government of Canada, Canadian Institutes of Health Research, [Personalized Medicine overview](#), 12 December 2013.
4. See, for example, Office of the Privacy Commissioner of Canada, "[The Predictive Value of Genetic Information: A Conversation with Dr. Steve Scherer, Director, the Centre for Applied Genomics, the Hospital for Sick Children and Professor of Medicine, University of Toronto](#)," *Privacy Research Papers*, December 2012. See also: Yann Joly, Maria Braker, and Michael Le Huynh, "[Genetic discrimination in private insurance: global perspectives](#)," *New Genetics and Society*, 2010, Vol. 29, Issue 4, pp. 351–368.
5. National Center for Biotechnology Information (U.S.), [GTR: Genetic Testing Registry](#).

6. Several journals and websites have reported the story of a teacher in Germany who was refused a permanent job because her father had Huntington's disease, a genetic disorder, and she was seen as having a high risk of developing the illness herself. She opposed genetic testing and successfully fought the decision. A German court found the refusal to be discriminatory and ruled that she should be entitled to a lifelong job. See, for example, PHG Foundation, [German government drafts legislation to allow genetic tests in employment](#), 25 October 2004; or Dagmar Schmitz and Urban Wiesing, [Just a family medical history?](#), 2006. See also "[Genetic discrimination investigated in Australia](#)," *BioNews*, 4 November 2005; and Stephanie Reitz and Douglas S. Malan, "[Genetic Tests Spark New Type Of Litigation](#)," *Connecticut Law Tribune*, 3 May 2010.
7. See, for example, Joseph Hall, "[Study finds genetic discrimination by insurance firms](#)," *The Toronto Star*, 9 June 2009; and Canadian Broadcasting Corporation, "[Genetic Discrimination](#)," *The National*, 12 February 2012.
8. Senate, Standing Committee on Human Rights, [Evidence](#), 2 October 2014 (Yvonne Bombard and Ronald Cohn).
9. Government of Canada, Health Canada, [Human Genome Project](#), 25 November 2005.
10. United Nations Educational, Scientific and Cultural Organization [UNESCO], [Universal Declaration on the Human Genome and Human Rights](#), 11 November 1997.
11. UNESCO, [International Declaration on Human Genetic Data](#), 16 October 2003. See also The United Nations Economic and Social Council, "[Resolution 2004/09: Genetic privacy and non-discrimination](#)," 2004, which urges states to take appropriate measures to "ensure that no one shall be subjected to discrimination based on genetic information."
12. Council of Europe, [Convention for the protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine](#), CETS No. 164.
13. Council of Europe Treaty Office, [Treaty status as of 21 October 2009](#).
14. According to Alexander Somek, Article 11 "is intended to sweep so broadly as to rule out any kind of genetic discrimination." Alexander Somek, "Genetic Discrimination," *Society*, Vol. 40, No. 6, September/October 2003, pp. 35–43.
15. Council of Europe, [Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Genetic Testing for Health Purposes](#), CETS No. 203.
16. Council of Europe, [Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Genetic Testing for Health Purposes](#), [Status as of 14 November 2014](#).
17. Trudo Lemmens, "[Genetics and Insurance Discrimination: Comparative Legislative, Regulatory and Policy Development and Canadian Options](#)," *Health Law Journal*, 2003, pp. 41–86; see also: Trudo Lemmens, Daryl Pullman and Rebecca Rodal, "[Revisiting Genetic Discrimination Issues in 2010: Policy Options for Canada](#)," GPS Policy Brief No. 2, 15 June 2010.
18. Discrimination on the ground of genetic status is prohibited by in Australia by national, state and territorial anti-discrimination laws. See Australian Government, National Health and Medical Research Council, [Genetic discrimination](#), NHMRC Ref. no. G1, November 2013.
19. See, for example, European Commission, "[Germany](#)," as discussed in *Community Research, Genetic Testing: Patient's rights, insurance and employment, A survey of regulations in the European Union*, 2002.
20. France, [Code du travail](#) [Labour Code], article L1132-1.
21. France, [Code de la santé publique](#) [Public Health Code], article L1141-1.

22. France, [Code civil](#) [Civil Code], article 16-13.
23. France, [Code de la santé publique](#) [Public Health Code], article R1131-1.
24. France, [Code civil](#) [Civil Code], article 16-10 and [Code de la santé publique](#) [Public Health Code], article R1131-1.
25. France, [Code pénal](#) [Penal Code], article 226-26.
26. United States, [Genetic Information Nondiscrimination Act of 2008](#), 110th Congress (2007–2008), H.R. 493.
27. National Human Genome Research Institute, "[Genetic Information Nondiscrimination Act of 2008](#)," *Fact Sheets*, 9 January 2009.
28. The Equal Employment Opportunity Commission will investigate and attempt to mediate any complaints. If this fails, the individual may sue the employer in a state or federal court for any violation of the GINA.
29. United States, *Genetic Information Nondiscrimination Act of 2008*, s. 206.
30. *Ibid.*, s. 202.
31. *Ibid.*, s. 101.
32. *Ibid.*, s. 102.
33. For example, an insured person could make a claim for payment if he or she has been diagnosed with a particular medical condition (for instance, cancer) after exposure to a toxic substance at the workplace. If tests were to reveal that this person was in fact genetically predisposed to develop this type of cancer at some point in his or her life, this may affect the evaluation of the harm or damage sustained as a result of the workplace exposure. Accordingly, this could affect the amount of the payment the person receives from the insurance provider. Such a reading of GINA is not necessarily contrary to the principle it explicitly sets out that genetic testing may not be used to discriminate against a person in providing insurance coverage or in calculating premiums or contribution amounts.
34. For more information on this review, see Department of Communities and Local Government (United Kingdom), [Discrimination Law Review, A Framework for Fairness: Proposals for a Single Equality Bill for Great Britain](#), Consultation paper, June 2007.
35. United Kingdom, *Data Protection Act 1998*, 1998 c. 29.
36. Association of British Insurers, [Concordat and Moratorium on Genetics and Insurance, 2011](#). The *Concordat and Moratorium* has been extended to 2017, see Association of British Insurers, "[Insurance Genetics Moratorium extended to 2017](#)," News release, 5 April 2011.
37. The Genetics and Insurance Committee was wound up on 1 July 2009 after approving only the test for Huntington's disease. It is not clear at this time whether another organization will be mandated to fulfil the same role. See Department of Health, [Genetics and Insurance Committee \(GAIC\)](#), Archived website, 6 May 2012; and Department of Health, "[Insurers continue to safeguard cover for those taking predictive genetic tests](#)," News release, 26 June 2012.
38. *Concordat and Moratorium on Genetics and Insurance*, 2011, paras. 31–33.
39. There are also pieces of federal legislation that deal with matters specific to genetic information, such as the [DNA Identification Act](#), S.C. 1998, c. 37, which created the national DNA "databank" containing genetic samples taken from convicted criminal offenders.

40. Lilith Finkler et al., "[Understanding the Use of 'Genetic Predisposition' in Canadian Legal Decisions](#)," *McGill Journal of Law and Health*, 2013, Vol. 7, No. 1, pp. 1 – 65. A similar caution against overemphasizing the importance of genetic factors over other health risks was argued in: Elizabeth A. Adjin-Tettey, "[Potential for Genetic Discrimination in Access to Insurance: Is there a Dark Side to Increased Availability of Genetic Information?](#)," *Alberta Law Review*, 2013, Vol. 50, No. 3, pp. 577–614.
41. [Constitution Act, 1867](#), 30 & 31 Victoria, c. 3 (U.K.).
42. Under section 92, provinces may pass laws under such heads of power as "property and civil rights," "shop ... and other licences," and "generally all matters of a merely local or private nature in the province." These powers allow a province to pass human rights laws concerning all matters involved in the provision of services, employment, and accommodation within the province. These laws therefore govern, to name a few, provincially registered or incorporated businesses; landlords; provincial government officials, agencies or other organizations; employers; and service providers in general.

Under section 91, federal laws may apply to, among other things, the "regulation of trade and commerce," or generally to promote "peace, order, and good government." The jurisdiction of the *Canadian Human Rights Act* covers employment, accommodation and services provided by the federal government and extends to federally regulated corporations and other persons or institutions under federal regulation.
43. Canada's human rights laws create complaints-based mechanisms wherein a person found to be engaging (or having engaged) in a discriminatory practice based on certain enumerated grounds may be ordered to cease doing so or take other remedial action and perhaps be penalized by a human rights tribunal.
44. [Canadian Human Rights Act](#), R.S.C., 1985, c. H-6.
45. Part I of the *Constitution Act, 1982*, being schedule B to the *Canada Act 1982* (U.K.), 1982, c. 11.
46. [Andrews v. Law Society of British Columbia](#), [1989] 1 S.C.R. 143, [Egan v. Canada](#), [1995] 2 S.C.R. 513, [Miron v. Trudel](#), [1995] 2 S.C.R. 418 and [Corbiere v. Canada \(Minister of Indian and Northern Affairs\)](#), [1999] 2 S.C.R. 203 respectively.
47. [Corbiere v. Canada \(Minister of Indian and Northern Affairs\)](#), [1999] 2 S.C.R. 203, para. 13.
48. The Office of the Privacy Commissioner of Canada has also described Canada's existing human rights laws as "potentially relevant." See Office of the Privacy Commissioner of Canada, [Genetic Information, the Life and Health Insurance Industry and the Protection of Personal Information: Framing the Debate](#), December 2012.
49. [Quebec \(Commission des droits de la personne et des droits de la jeunesse\) v. Montréal \(City\); Quebec \(Commission des droits de la personne et des droits de la jeunesse\) v. Boisbriand \(City\)](#), [2000] 1 S.C.R. 665.
50. [Charter of Human Rights and Freedoms](#), R.S.Q., c. C-12.
51. Lemmens (2003), p. 50.
52. Canadian Human Rights Act Review Panel, *The Report of the Canadian Human Rights Act Review Panel*, Recommendation 119, June 2000.
53. [Bill C-508: An Act to amend the Canadian Human Rights Act \(genetic characteristics\)](#), 3rd Session, 40th Parliament; and [Bill C-536: An Act to amend the Canadian Human Rights Act \(genetic characteristics\)](#), 3rd Session, 40th Parliament.

54. [Bill C-445: An Act to amend the Canadian Human Rights Act \(genetic characteristics\)](#), 2nd Session, 41st Parliament. Bill C-445 was introduced by Member of Parliament Libby Davies on 1 October 2012 during the 41st Parliament, and was reinstated on 16 October 2013.
55. [Bill S-201: An Act to prohibit and prevent genetic discrimination](#), 2nd Session, 41st Parliament.
56. [Canada Labour Code](#), R.S.C., 1985, c. L-2.
57. Also, no other person would be permitted to disclose to the employer the results of an employee's genetic test, or that an employee has taken a test, and the employer may not receive or use such test results without the written consent of the employee. The bill also proposes a complaint mechanisms for employees who feel they have been discriminated against.
58. The proposed law would create exemptions for persons providing medical care or conducting scientific research. Also, the proposed section 6 would permit the disclosure of the results of genetic tests already taken where "a contract of insurance for an amount that exceeds \$1,000,000 or that pays a benefit of more than \$75,000 per annum" and where this is already permitted by provincial laws.
59. Senate, Standing Committee on Human Rights, [Evidence](#), 2nd Session, 41st Parliament, 29 September 2014 (Senator James Cowan).
60. Ontario, [Bill 127: An Act to amend the Human Rights Code with respect to genetic characteristics](#), 2nd Session, 40th Legislature.
61. The Canadian Coalition for Genetic Fairness, a non-government organization whose membership includes a number of national health advocacy groups, has been advocating for a Canadian law to address genetic discrimination. See: [About CCGF](#), 2009. See also endnotes 38 and 90.
62. [Personal Information Protection and Electronic Documents Act \(PIPEDA\)](#), S.C. 2000, c. 5.
63. See, for example, [Personal Information Protection Act](#), S.B.C. 2003, c. 63; [Personal Information Protection Act](#), S.A. 2003, c. P-6.5; and [Loi sur la protection des renseignements personnels dans le secteur privé](#), L.R.Q., ch. P-39.1.
64. The *Personal Information Protection and Electronic Documents Act* [PIPEDA] applies to all provinces, unless a province has passed its own private sector privacy legislation that is deemed "substantially similar" to PIPEDA by a declaration of the Governor in Council. Such provincial legislation replaces PIPEDA within that province, except where matters relating to interprovincial or federally regulated commercial activity are involved. (Currently, British Columbia, Alberta and Quebec have substantially similar legislation that replaces PIPEDA.) In addition, many of the provinces have passed statutes related to the privacy of health information. Those that have been determined to be "substantially similar" are available on the [Privacy Commissioner's website](#). PIPEDA continues to apply to the private sector in all other provinces, and to private sector commercial activity that does not involve health information custodians or health information in Ontario.
65. An example would be Ontario, [Personal Health Information Protection Act](#), S.O. 2004, c. 3, Schedule A. Alberta also has its own [Health Information Act](#) (R.S.A. 2000, c. H-5), as do several other provinces, but because this legislation has not been declared "substantially similar" to PIPEDA by the Governor in Council, its applicable jurisdiction is more limited. Alberta's Act, for example, applies under provincial jurisdiction to all doctors paid out of the Alberta Health Care Insurance Plan to provide services, but would not necessarily apply to doctors in private clinics who do not receive this funding.
66. Private employers are covered by PIPEDA, except in Alberta, British Columbia, and Quebec, which have their own "substantially similar" private sector privacy legislation.

67. All the provinces and territories have some form of privacy legislation that governs how public sector institutions handle personal information. The law that applies to the public sector at the federal level is the [Privacy Act](#), R.S.C. 1985, c. P-21.
68. There are certain exemptions from the consent requirement in the Act, including collection, use and disclosure of personal information with respect to emergencies that threaten life, health and safety, as well as law enforcement investigations and activities. The detailed list of exemptions can be found in section 7 of PIPEDA.
69. PIPEDA, s. 5; and Schedule 1, ss. 4.2.3 and 4.3.2.
70. *Ibid.*, Schedule 1, ss. 4.3.4 and 4.3.6.
71. *Ibid.*, s. 4.7.2.
72. Office of the Privacy Commissioner of Canada, [Genetic Information, the Life and Health Insurance Industry and the Protection of Personal Information: Framing the Debate](#), 21 December 2012.
73. Stephen Orr, "Privacy of Genetic Information in Canada: A Brief Examination of the Legal and Ethical Tools That Should Frame Canada's Regulatory Response," *Canadian Journal of Law and Technology*, November 2004, Vol. 3, No. 3, pp. 127–140.
74. Trudo Lemmens, Lori Luther, and Michael Hoy, "Genetic Information Access, a Legal Perspective: A Duty to Know or a Right Not to Know, and a Duty or Option to Warn," *Encyclopaedia of Life Sciences*, John Wiley & Sons Ltd., Chichester, 15 July 2008.
75. Michael Hoy and Maureen Durnin, *The Potential Economic Impact of a Ban on the Use of Genetic Information for Life and Health Insurance*, March 2012; Angus Macdonald, "The Actuarial Relevance of Genetic Information in the Life and Health Insurance Context," July 2011, available at Office of the Privacy Commissioner of Canada, [Privacy Research Papers](#), 12 December 2012.
76. Office of the Privacy Commissioner, [Genetic Information: Consent, Privacy and Research Biobanks – Remarks at the Genome Canada/Office of the Privacy Commissioner Workshop](#), 27 November 2009.
77. PIPEDA, s. 11.
78. Case summaries pertaining to the federal Privacy Commissioner's findings about insurance companies are available on the [Privacy Commissioner's website](#). The Commissioner's authority in such matters was challenged in [State Farm Mutual Automobile Insurance Company v. Privacy Commissioner of Canada](#), 2010 FC 736, T-604-09. The Federal Court did not address this issue in its decision, however. See also: Office of the Privacy Commissioner, [Recent Court Activity – State Farm Mutual Automobile Insurance Company v. Privacy Commissioner of Canada and Attorney General of Canada](#), 22 December 2010.
79. Not all matters contained in PIPEDA can be litigated, but most substantive issues under the legislation, i.e., those that concern the key privacy principles and protections in Schedule 1, can be brought to the courts (see PIPEDA, s. 14).
80. PIPEDA, s. 14.
81. *Ibid.*, s. 15.
82. *Ibid.*, s. 16.
83. See, for example, [Human Rights Code](#), R.S.O. 1990, c. H.19, ss. 22 and 25.
84. *Ontario (Human Rights Commission) v. Zurich Ins. Co.* (1992), 16. C.H.R.R. D/255 (S.C.C.).

GENETIC DISCRIMINATION AND CANADIAN LAW

85. Although the subjects of “insurance,” “insurance law” or “insurance contracts” are not specifically enumerated under either section 91 or section 92 of the *Constitution Act, 1867*, Canadian courts consider insurance and insurance law to be, for the most part, a matter of “property and civil rights in the province” under section 92(13) of the *Constitution Act, 1867*.
86. It is not necessary to be a federally incorporated entity in order for the [Insurance Companies Act](#), S.C. 1991, c. 47 to apply. Some portions of the *Insurance Companies Act* also apply to provincially incorporated insurance companies and foreign insurance companies. These companies can also apply for a certificate of continuance under the Act if they so choose, and if the jurisdiction under which they were originally incorporated so permits. At that point, these companies become fully federally regulated.
87. *Insurance Companies Act*, S.C. 1991, c. 47.
88. See, for example, *Citizens Insurance Co. v. Parsons* (1881), 7 App. Cas. 96 (J.C.P.C.); *Reference re Insurance Companies*, [1916] 1 A.C. 588 (J.C.P.C.); *Re Reciprocal Insurance Legislation*, [1924] 1 D.L.R. 789 (J.C.P.C.); *Re Insurance Act and Special War Revenue Act*, [1932] 1 D.L.R. 97 (J.C.P.C.); *Re s. 16 of the Special War Revenue Act*, [1942] S.C.R. 429, leave to appeal refused [1943] 4 D.L.R. 657 (J.C.P.C.); *Unemployment Insurance Reference*, [1937] A.C. 355 (J.C.P.C.); *Canadian Indemnity Co. v. British Columbia (Attorney General)*, [1977] 2 S.C.R. 504; *Canadian Pioneer Management Ltd. v. Saskatchewan (Labour Relations Board)*, [1980] 1 S.C.R. 433.
89. [Insurance Act](#), R.S.O. 1990, c. I.8.
90. See Canadian Life and Health Insurance Association, [CLHIA position statement on genetic testing](#), April 2010; and Canadian Institute of Actuaries, [Statement on Genetic Testing and Insurance](#), June 2014.
91. In Quebec, this obligation is found under Articles 2408, 2409, and 2410 of the *Civil Code*, LRQ, c C-1991. If it is not complied with, the insurer is allowed to cancel the policy at any time. Other provinces and territories have similar requirements and consequences contained in their insurance acts.
92. Senate, Standing Committee on Human Rights, [Evidence](#), 2nd Session, 41st Parliament, 29 September 2014.
93. See, for example, Yann Joly, “[Do we need legislation to protect Canadians’ genetic rights? The No side](#),” *The Globe and Mail*, 10 December 2012; Bev Heim-Meyers, “[Do we need legislation to protect Canadians’ genetic rights? The Yes side](#),” *The Globe and Mail*, 10 December 2012.
94. National Human Genome Research Institute, [Genetic Information Nondiscrimination Act of 2008](#).