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## LEGISLATIVE SUMMARY



# **Bill C-68: An Act to amend the Canadian Human Rights Act, the Privacy Act and the Personal Information Protection and Electronic Documents Act**

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**Maxime-Olivier Thibodeau  
Julian Walker**

Legal and Social Affairs Division  
Parliamentary Information and Research Service

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Any substantive changes in this Legislative Summary that have been made since the preceding issue are indicated in **bold print**.

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*Legislative Summary of Bill C-68*  
(Legislative Summary)

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# LEGISLATIVE SUMMARY OF BILL C-68: AN ACT TO AMEND THE CANADIAN HUMAN RIGHTS ACT, THE PRIVACY ACT AND THE PERSONAL INFORMATION PROTECTION AND ELECTRONIC DOCUMENTS ACT

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## 1 BACKGROUND

Bill C-68, An Act to amend the Canadian Human Rights Act, the Privacy Act and the Personal Information Protection and Electronic Documents Act (short title: Protection Against Genetic Discrimination Act) was introduced in the House of Commons on 9 June 2015 by the Honourable Peter MacKay, Minister of Justice and Attorney General of Canada.<sup>1</sup> It died on the Order Paper upon the dissolution of the 41<sup>st</sup> Parliament.

Bill C-68 amends three pieces of federal legislation to address concerns that discrimination and violations of privacy rights could result when a person's genetic information is shared with others. It adds a new provision to the *Canadian Human Rights Act* (CHRA)<sup>2</sup> that extends existing prohibitions against discriminatory practices in order to protect people who, through genetic testing, have learned that they are predisposed to acquire a disability (i.e., they have a genetic risk factor for a disabling condition). Disability is already listed as one of the grounds under the CHRA upon which it is prohibited to discriminate against someone. Any discrimination against a person based on the results of genetic testing would be deemed under the Act to fall within this existing ground.

The bill also amends the *Privacy Act*<sup>3</sup> and the *Personal Information Protection and Electronic Documents Act* (PIPEDA)<sup>4</sup> to specifically include information resulting from genetic testing within existing definitions of the types of personal information that are protected by these laws.

### 1.1 GENETIC DISCRIMINATION AND GENETIC PRIVACY<sup>5</sup>

Genetic testing refers to the process of analyzing a person's genes to identify specific traits or markers. The identification of genetic markers can help medical professionals diagnose existing diseases and conditions and determine the most appropriate pharmaceutical or other treatment for a patient; genetic markers can also identify a predisposition to certain conditions and thus enable early intervention. Genetic markers can also be useful for non-medical purposes, such as identifying a person's ancestral origins, establishing whether two people are related, or determining whether a person is responsible for committing a particular crime.

If genetic testing reveals there is a risk that a person could develop a genetic condition or disease, this could affect his or her prospects of obtaining appropriate life or disability insurance coverage or of being hired by an employer. Prospective insurers or employers might discriminate against the person if they fear that entering into a contract with him or her could lead to higher costs or increased inconvenience

in the future. Fears that genetic information could prompt discriminatory behaviour of this kind have prompted calls for legislation to minimize that risk.

There have also been calls to provide greater legal protection of genetic information for the sake of people's privacy rights. As more services are being offered that make use of genetic information, the protection of that information has become a key issue. A great deal of personal information can be gleaned from a person's genetic code, ranging from identity to health status to ethnic and familial origins.<sup>6</sup> An additional challenge for policy makers is the fact that family members share many of the same genes. If someone has access to one person's genetic test results, this will reveal much about their family members. In light of such concerns, the Office of the Privacy Commissioner of Canada has made the protection of genetic information one of its policy priorities in recent years.<sup>7</sup>

Although some provinces have begun to implement some protection for genetic information in their privacy legislation,<sup>8</sup> at present no federal laws cover the use of genetic information or prohibit discrimination on the basis of genetic characteristics. It is possible that, if a genetic discrimination case were to proceed in court, the *Canadian Human Rights Act*, *Privacy Act* and PIPEDA might be interpreted as already providing some protection from genetic discrimination and some protection of the privacy of genetic information; however, no such case has yet to proceed in Canada.<sup>9</sup> Various organizations, legal experts and other commentators have debated the need to pass legislation in Canada to explicitly address these issues.<sup>10</sup>

The prevalence of genetic discrimination in Canada and other countries remains an open question: commentators and organizations claim, variously, that it is already an issue, that there is no evidence that it is a problem, or that there is not enough reliable information on which to base conclusive statements.<sup>11</sup> An academic study of recent case law noted that while no court or tribunal has yet to specifically examine genetic discrimination, this "does not suggest that" such discrimination is not taking place.<sup>12</sup> When the Standing Senate Committee on Human Rights studied these issues, witnesses testified that some medical patients have been discriminated against on the basis of their genetic information, while some others have declined potentially beneficial genetic testing because it could compromise their ability to obtain insurance.<sup>13</sup> What is certain is that the number of reliable genetic tests is increasing, as are the ways in which such information is being used<sup>14</sup> and the services that are being offered to help individuals understand their test results.<sup>15</sup>

In the absence of a law that explicitly regulates the use of genetic test results by insurers in Canada, the Canadian Life and Health Insurance Association, the Canadian Institute of Actuaries, and the Canadian Life Insurance Medical Officers Association have taken the position that they will not require genetic testing of applicants for insurance, but will require disclosure of any existing test results.<sup>16</sup>

Concern about the consequences of genetic discrimination has prompted varied responses in recent years from governments and international organizations. Some countries, such as Australia, France and the United States,<sup>17</sup> have passed laws to prohibit certain forms of genetic discrimination.<sup>18</sup> The United Kingdom has taken a different approach by permitting its insurance industry to adopt a self-regulating

policy that limits how genetic information may be used.<sup>19</sup> UNESCO (the United Nations Educational, Scientific and Cultural Organization) has passed resolutions addressing the use of human genetics, such as the 1997 *Universal Declaration on the Human Genome and Human Rights* (which was also endorsed by the General Assembly in 1998).<sup>20</sup> Among other things, this instrument is intended to prevent genetic discrimination and any use of genetic information that would be contrary to human dignity and human rights.

## 1.2 THE CANADIAN HUMAN RIGHTS ACT

The *Canadian Human Rights Act* is human rights legislation that applies to the federal sector, including federal government departments and agencies, Crown corporations, and federally regulated businesses. Section 3(1) of the Act prohibits discrimination on the basis of specified grounds, such as race, sex, age, religion, and disability, in the context of employment, accommodation and publicly available services. The Act specifically prohibits “discriminatory practices,” such as denying a good, service or accommodation; refusing to employ a person; and excluding a person from membership in an organization (sections 5 to 14.1 of the Act). The Canadian Human Rights Commission refers to discrimination as “an action or a decision that treats a person or a group negatively for reasons such as their race, age or disability.”<sup>21</sup> Section 2 of the CHRA places a positive duty on employers and service providers to take reasonable steps to accommodate people’s needs in order to prevent discrimination on the prohibited grounds.<sup>22</sup>

The CHRA allows a person who feels that his or her rights under the Act have been infringed upon or violated to make a complaint to or seek the assistance of the Canadian Human Rights Commission. The Commission will attempt to mediate any dispute between parties; if this is unsuccessful, the complaint may be referred to the Canadian Human Rights Tribunal for adjudication.

Canadian provinces and territories also have human rights laws that apply to matters within their own jurisdictions (including public institutions such as schools and most private-sector employment, services and accommodation matters). Canadian courts have considered these laws to have quasi-constitutional status, thereby giving the rights they contain greater protection.<sup>23</sup>

## 1.3 PRIVACY LEGISLATION

The primary pieces of federal privacy legislation are the *Privacy Act*, which applies to personal information within federal jurisdiction, and the *Personal Information Protection and Electronic Documents Act* (PIPEDA), which applies to the private sector.

### 1.3.1 THE PRIVACY ACT

The *Privacy Act* protects the personal information of identifiable individuals and guarantees them a right of access to that information. Personal information protected by the *Privacy Act* is information held by federal institutions: that is, government departments and agencies set out in the Schedule of the Act, and Crown

corporations, whether parent Crown corporations or wholly-owned subsidiaries within the meaning of section 83 of the *Financial Administration Act*.<sup>24</sup>

Under the *Privacy Act*, the federal government must protect the privacy of individuals by controlling the collection, use, disclosure, retention and disposal of their personal information. Provinces and territories have enacted similar legislation applicable to their respective public sectors and the personal information they maintain.

### 1.3.2 THE *PERSONAL INFORMATION PROTECTION AND ELECTRONIC DOCUMENTS ACT*

PIPEDA establishes ground rules for the management of personal information in the private sector. It aims to strike a balance between the right to privacy and the need of organizations to collect, use and disclose personal information for legitimate business purposes.

PIPEDA applies to organizations engaged in commercial activities across Canada, except those governed by provinces with legislation that is “substantially similar” to the federal legislation. Alberta, British Columbia and Quebec have enacted legislation deemed substantially similar to PIPEDA. Ontario, New Brunswick and Newfoundland and Labrador have enacted legislation deemed substantially similar to PIPEDA with respect to health. In all provinces, PIPEDA applies to federally regulated private-sector organizations and to personal information involved in interprovincial and international transactions.

## 1.4 PREVIOUS BILLS

During the 40<sup>th</sup> and 41<sup>st</sup> Parliaments, four bills were introduced that proposed to provide some protection against genetic discrimination by adding “genetic characteristics” to the list of prohibited grounds of discrimination in the CHRA. All of these bills died on the Order Paper. Three were private members’ bills introduced in the House of Commons.<sup>25</sup> Bill S-201<sup>26</sup> was introduced in the Senate in 2013 and would have also added new sections to the *Canada Labour Code*<sup>27</sup> (the main employment law within federal jurisdiction). The aim of the proposed legislation was, among other things, to protect an employee’s right not to be required to take a genetic test or to disclose the results of a test already taken, and to prohibit employers from engaging in discriminatory practices on the basis of a person’s genetic characteristics. The bill also included criminal sanctions against requiring another person to undergo a genetic test or to disclose the results of a test as a condition of providing goods or services or entering into a contract.

## 2 DESCRIPTION AND ANALYSIS

### 2.1 AMENDMENTS TO THE *CANADIAN HUMAN RIGHTS ACT*

Clause 2 of Bill C-68 adds a new subsection to section 3 of the CHRA. As noted above, the Act prohibits people and organizations from engaging in discriminatory



practices toward a person on certain grounds, such as race, disability, sex and religion. Section 3(1) sets out the list of these prohibited grounds of discrimination.

Existing section 3(2) clarifies that where discrimination is based on pregnancy or childbirth, this will be considered to be on the ground of sex. Similarly, clause 2 adds section 3(3) to clarify that where the discrimination is based on a predisposition to disability that is inferred from the results of genetic testing, then this will fall under the ground of disability. This clarification ensures that existing case law that has helped develop a more comprehensive understanding of the existing ground of disability would be applicable to any complaints related to genetic discrimination brought under the CHRA.

The impact of this new provision is limited to the federal sector; therefore, the majority of commercial contracts that are entered into in Canada will not be affected, since these fall under provincial jurisdiction. In particular, the new provision will not have an impact on most insurance contracts, since these are covered at the provincial level, where human rights laws tend to make certain exceptions for the insurance industry that allow discrimination on such grounds as age, sex and disability.

## 2.2 AMENDMENTS TO THE *PRIVACY ACT*

Clause 3 amends the non-exclusive list of what constitutes “personal information” under section 3 of the *Privacy Act*, adding a new paragraph (*d.1*), which states that “personal information” about an identifiable individual includes “information resulting from genetic testing of the individual.”<sup>28</sup> The courts have consistently taken a broad interpretation of the definition of “personal information” under section 3 of the *Privacy Act*.<sup>29</sup>

## 2.3 AMENDMENTS TO THE *PERSONAL INFORMATION PROTECTION AND ELECTRONIC DOCUMENTS ACT*

Clause 4 changes the heading “Définitions” before section 2 of the French version of PIPEDA by adding the words “et interprétation.” The heading before section 2 of the English version of PIPEDA, “Interpretation,” is left unchanged.

Section 2(1) of PIPEDA sets out the definitions that apply to Part 1 of the Act, which covers the protection of personal information in the private sector (Part 2 covers electronic documents). This section defines “personal information” as “information about an identifiable individual.”<sup>30</sup>

Clause 5 adds a new section 2(1.1) to PIPEDA, which reads as follows:

For greater certainty, personal information includes personal health information, such as information derived from genetic testing.

Since the new section 2(1.1) added by the bill states that information derived from genetic testing is included in personal health information, logically the amendments made by the bill should not apply to those provinces that enacted legislation deemed “substantially similar” to PIPEDA with respect to health.

For example, in New Brunswick, the definition of “personal health information” in the *Personal Health Information Privacy and Access Act*<sup>31</sup> explicitly covers identifying information about an individual that “relates to the individual’s physical or mental health, family history or health care history, including genetic information about the individual” and “relates to the donation by the individual of any body part or bodily substance of the individual or is derived from the testing or examination of any body part or bodily substance.”<sup>32</sup>

Newfoundland and Labrador’s *Personal Health Information Act*<sup>33</sup> states that an individual who meets the definition of “custodian,”<sup>34</sup> namely an individual listed in the Act who has custody or control of another individual’s personal health information,

may collect personal health information from a source other than the individual who is the subject of the information where ... the information is to be collected for the purpose of assembling a family or genetic history where the information collected will be used in the context of providing a health service to the individual.<sup>35</sup>

This authorizes these individuals to collect another individual’s genetic information for the purpose of providing that individual with health services; this does not involve protecting this information from a privacy perspective.

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## NOTES

1. [Bill C-68: An Act to amend the Canadian Human Rights Act, the Privacy Act and the Personal Information Protection and Electronic Documents Act](#), 2<sup>nd</sup> Session, 41<sup>st</sup> Parliament.
2. [Canadian Human Rights Act](#), R.S.C., 1985, c. H-6.
3. [Privacy Act](#), R.S.C., 1985, c. P-21.
4. [Personal Information Protection and Electronic Documents Act](#) (PIPEDA), S.C. 2000, c. 5.
5. For more information regarding this topic, see: Julian Walker, [Genetic Discrimination and Canadian Law](#), Publication no. 2014-90-E, Parliamentary Information and Research Service, Library of Parliament, Ottawa, 16 September 2014.
6. In one published study, a research team managed to show how identities of participants in a public genetic genealogy database could be inferred by triangulating short genetic sequences with surnames and demographic metadata; the identities of the participants were intended to be private. This demonstrated how the privacy rights of participants could be violated and their genetic information accessed. Melissa Gymrek et al., [“Identifying Personal Genomes by Surname Inference,”](#) *Science*, Vol. 339, No. 6117, 18 January 2013, pp. 321–324.
7. Senate, Standing Committee on Human Rights, [Evidence](#), 2 October 2014 (Daniel Therrien, Privacy Commissioner of Canada). See also, for example, Office of the Privacy Commissioner of Canada, [Statement on the use of genetic test results by life and health insurance companies](#), 10 July 2014.
8. See section 2.3 in this paper for information about laws passed by New Brunswick and Newfoundland and Labrador.

9. A review of Canadian case law is presented in 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.
10. 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; and [Canadian Coalition for Genetic Fairness](#).
11. See, for example, Joseph Hall, "[Study finds genetic discrimination by insurance firms](#)," *The Toronto Star*, 9 June 2009; Canadian Broadcasting Corporation, "[Genetic Discrimination](#)," *The National*, 12 February 2012; Yann Joly, Ida Ngueng Feze and Jacques Simard, "[Genetic discrimination and life insurance: a systematic review of the evidence](#)," *BMC Medicine*, Vol. 11, No. 25, 2013; and Australian Law Reform Commission, [Essentially Yours: The Protection of Human Genetic Information in Australia](#), ALRC Report 96, 30 May 2003.
12. Finkler et al. (2013).
13. Senate, Standing Committee on Human Rights, [Evidence](#), 2 October 2014 (Yvonne Bombard and Ronald Cohn).
14. As an example, the emerging field of personalized medicine, which uses genetic information and other biomarkers to tailor therapies to individual patients, is being promoted as a means of improving health care and reducing health care costs. See Government of Canada, Canadian Institutes of Health Research, "[Personalized Medicine overview](#)," 12 December 2013.
15. For examples of the types of services being offered, please note the links on the following websites: National Center for Biotechnology Information (U.S.), [GTR: Genetic Testing Registry](#); and [Canadian Association of Genetic Counsellors](#).
16. 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.
17. For more information concerning approaches to genetic discrimination by foreign governments, see Walker (2014), section 2.2.
18. Australia, [Disability Discrimination Act 1992](#). (Note: This is a federal law; there are also anti-discrimination laws that apply at the state level.) France, [Code du travail](#) [Labour Code], article L1132-1; [Code de la santé publique](#) [Public Health Code], article L1141-1 and R1131-1; [Code civil](#) [Civil Code], articles 16-10 and 16-13; and [Code pénal](#) [Penal Code], article 226-26. United States, [Genetic Information Nondiscrimination Act of 2008](#), 110<sup>th</sup> Congress (2007–2008), H.R. 493.
19. 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. Guidelines for the insurance industry from the Human Rights Commission in New Zealand state that "[i]nsurance companies can request applicants to disclose the results of any genetic tests"; see: New Zealand, Human Rights Commission, [Guidelines: Insurance and the Human Rights Act 1993](#), revised 2007.
20. UNESCO, [Universal Declaration on the Human Genome and Human Rights](#), Geneva, 11 November 1997.
21. Canadian Human Rights Association, "[What is discrimination?](#)"

22. For more information, see Laura Barnett, Julia Nicol and Julian Walker, [An Examination of the Duty to Accommodate in the Canadian Human Rights Context](#), Publication no. 2012-01-E, Parliamentary Information and Research Service, Library of Parliament, Ottawa, 10 January 2012.
23. As noted in *Insurance Corp. of British Columbia v. Heerspink*, [1982] 2 S.C.R. 145; and *Zurich Insurance Co. v. Ontario (Human Rights Commission)*, [1992] 2 S.C.R. 321.
24. Section 83 of the [Financial Administration Act](#) defines a “parent Crown corporation” as “a corporation that is wholly owned directly by the Crown, but does not include a departmental corporation” and defines a “wholly-owned subsidiary” as “a corporation that is wholly owned by one or more parent Crown corporations directly or indirectly through any number of subsidiaries each of which is wholly owned directly or indirectly by one or more parent Crown corporations.”
25. [Bill C-508: An Act to amend the Canadian Human Rights Act \(genetic characteristics\)](#), 3<sup>rd</sup> Session, 40<sup>th</sup> Parliament; [Bill C-536: An Act to amend the Canadian Human Rights Act \(genetic characteristics\)](#), 3<sup>rd</sup> Session, 40<sup>th</sup> Parliament; and [Bill C-445: An Act to amend the Canadian Human Rights Act \(genetic characteristics\)](#), 2<sup>nd</sup> Session, 41<sup>st</sup> Parliament.
26. [Bill S-201: An Act to prohibit and prevent genetic discrimination](#), 2<sup>nd</sup> Session, 41<sup>st</sup> Parliament.
27. [Canada Labour Code](#), R.S.C., 1985, c. L-2.
28. Under section 3 of the *Privacy Act*, the expression “personal information” means information about an identifiable individual that is recorded in any form including, without restricting the generality of the foregoing,
- (a) information relating to the race, national or ethnic origin, colour, religion, age or marital status of the individual,
  - (b) information relating to the education or the medical, criminal or employment history of the individual or information relating to financial transactions in which the individual has been involved,
  - (c) any identifying number, symbol or other particular assigned to the individual,
  - (d) the address, fingerprints or blood type of the individual,
  - (e) the personal opinions or views of the individual except where they are about another individual or about a proposal for a grant, an award or a prize to be made to another individual by a government institution or a part of a government institution specified in the regulations,
  - (f) correspondence sent to a government institution by the individual that is implicitly or explicitly of a private or confidential nature, and replies to such correspondence that would reveal the contents of the original correspondence,
  - (g) the views or opinions of another individual about the individual,
  - (h) the views or opinions of another individual about a proposal for a grant, an award or a prize to be made to the individual by an institution or a part of an institution referred to in paragraph (e), but excluding the name of the other individual where it appears with the views or opinions of the other individual, and
  - (i) the name of the individual where it appears with other personal information relating to the individual or where the disclosure of the name itself would reveal information about the individual.

29. For example, see [\*Dagg v. Canada \(Minister of Finance\)\*](#), [1997] 2 S.C.R. 403; and [\*Canada \(Information Commissioner\) v. Canada \(Transportation Accident Investigation and Safety Board\)\*](#) (F.C.A.), 2006 FCA 157, [2007] 1 F.C.R. 203.
30. For applications in different contexts of the PIPEDA definition of “personal information,” see Office of the Privacy Commissioner, “[Interpretation Bulletin](#),” *Legal information related to PIPEDA*.
31. New Brunswick, [\*Personal Health Information Privacy and Access Act\*](#) (S.N.B. 2009, c. P-7.05), which is New Brunswick’s legislation deemed substantially similar to PIPEDA with respect to health.
32. *Ibid.*, section 1, “personal health information,” paras. (a) and (e).
33. Newfoundland and Labrador, [\*Personal Health Information Act\*](#), c. P-7.01, which is Newfoundland and Labrador’s legislation deemed substantially similar to PIPEDA with respect to health.
34. Section 4(1) of the *Personal Health Information Act* defines who is deemed a “custodian.”
35. *Personal Health Information Act*, s. 31(g).