

Genetic Discrimination

What is genetic discrimination?

Genetic discrimination occurs when people are treated differently because they have a gene mutation that causes or increases the risk of a hereditary disorder. Concern about genetic discrimination is largely concentrated on the realms of insurance and employment. Insurance companies may require genetic testing or access to the results of genetic testing, and may refuse to insure or charge higher premiums to individuals with genetic mutations. Employers may avoid hiring or promoting or may dismiss employees at risk of developing hereditary disorders in order to avoid higher disability insurance costs, reduce absenteeism and employee turnover, or protect their investments in employee training.

The incidence of genetic discrimination in Canada is likely quite low, but fear of genetic discrimination is much more common. For example, in a survey of people with a close family member suffering from Huntington's disease—and therefore at a significant risk of developing the disease themselves—fewer than half of respondents indicated that they had experienced genetic discrimination, but most (86%) feared genetic discrimination for themselves and for their family members.

How does genetic discrimination happen?

Several studies have revealed that fear of genetic discrimination, particularly in insurance and employment, prevents many Canadians from undergoing genetic testing. Genetic testing often provides valuable medical information and guides preventative or treatment measures. The same fear prevents many Canadians from participating in genetic research that can potentially identify new treatments for hereditary conditions.

Outside of Canada, many countries (including all the other G7 countries) have enacted laws to prevent genetic discrimination. These laws recognize the exceptional nature of genetic information which sets it apart from other kinds of personal health information. Genetic information differs from other kinds of health information in several regards: it can predict future health outcomes; it is a unique identifier; it can reveal information about family members or members of the same racial or ethnic group; and it is passed from parent to child. Given the rapid pace of advances in genetic science, it is very likely that new findings will generate increasingly sensitive knowledge about everyone.

Why is genetic discrimination an issue?

In Canada, previous federal governments have unsuccessfully attempted to pass genetic anti-discrimination laws. A new attempt is underway: Bill S-201, the Genetic Non-Discrimination Act, has been passed by the Senate and has been introduced to the House of Commons. The act would prohibit anyone from requiring genetic testing or requiring disclosure of the results of a genetic test as a condition of providing goods or services or of entering into or continuing a contract (with exceptions for health care professionals and researchers). This bill will be considered by the House of Commons in the next parliamentary session, but even if the bill is passed a federal law may not protect Canadians from genetic discrimination in insurance, which falls under the purview of provincial laws. To ensure Canadians are adequately protected from genetic discrimination, each province will also have to pass genetic anti-discrimination legislation.

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Ethical Issues

The Charter of Rights and Freedoms and the Canadian Human Rights Act provide protections against many different forms of discrimination, including discrimination on the basis of: race, national or ethnic origin, colour, religion, age, sex, sexual orientation, marital status, family status, disability, and pardoned convictions. In Canada, however, there are no specific protections against genetic discrimination.

More Information and Resources

http://www.ashg.org/pdf/policy/ASHG_PS_May_2016.pdf

<http://www.parl.gc.ca/HousePublications/Publication.aspx?DocId=6257111>

Visit **genomebc.ca** to learn more.