

# Some Canadians may still be at risk of genetic discrimination despite new federal law

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As Canadians share more and more genetic data with service providers such as insurance companies or databases like Ancestry.com, the potential for discrimination based on this data is growing. Known as genetic discrimination (GD), this practice is broadly defined as the differential treatment of an individual compared to the rest of the population based on actual or presumed genetic information. Although

the Genetic Non-Discrimination Act (GNDA) was passed in 2017 to protect Canadians from GD, a team at the Centre of Genomics and Policy of McGill University has found that many life insurance companies have found ways to circumvent these rules.

The study, [published](#) in *FACETS* and titled "Still using [genetic data](#)? A comparative review of Canadian life insurance application forms before and after the GNDA," was based on a comparative analysis of insurance applications forms pre- and post- GNDA. The team set out to assess the efficacy of the GNDA by focusing on the field of life insurance, where the risk of discrimination is said to be the highest. The results show that so far, the GNDA has only had a modest impact on the genetic discrimination practices of the Canadian life insurance industry.

The team compared and contrasted data on access to genetic information by Canadian life insurers through application forms. They found that the general use of broadly phrased questions allows insurers to work around the specific prohibitions of the law, and can mislead applicants to disclose genetic test results even when their use is prohibited. The GNDA makes it a criminal infraction to require testing or genetic test results disclosure as a condition for providing an individual with goods and services.

However, from the study, it is uncertain that the law has achieved its purpose of preventing genetic discrimination, because unscrupulous insurance providers may still access genetic information directly or indirectly.

"The GNDA is an important first step in the struggle to prevent genetic discrimination," said Professor Yann Joly, Director of the Centre of Genomics and Policy and co-author of the study. "A more coherent and comprehensive framework to protect genetic data, and meaningful citizen's engagement, will however, be needed, if genetic [discrimination](#)

is to truly be eliminated in Canada."

## Gaps in the law

This study was the first published assessment of the efficacy of the GNDA and found that there are gaps in the law that could be remedied by adopting additional policies at the provincial level. The study also raises the important question about the use of health data to determine insurance pricing, highlighting issues that are inextricably linked to the way private life insurance is run in Canada, such as a lack of transparency and ability to use broad questions on health questionnaires.

The Centre of Genomics and Policy of McGill University (CGP), located within the Victor Phillip Dahdaleh Institute of Genomic Medicine, is a multidisciplinary center that works on analyzing the socio-ethical and legal norms influencing the promotion, prevention, and protection of human health. The CGP, along with the International Genetic Discrimination Observatory, intends to run a second phase of the study in 2024 to gauge the real impact of these practices on Canadian consumers.

**More information:** Amy Fernando et al, Still using genetic data? A comparative review of Canadian life insurance application forms before and after the GNDA, *FACETS* (2024). [DOI: 10.1139/facets-2023-0101](https://doi.org/10.1139/facets-2023-0101)

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