

Genetic Non-Discrimination Act (GNDA)

Guidance for OCREB Reviewers [Revised June 2026]

With Acknowledgment to Dr. Yann Joly Ph.D. (DCL), FCAHS, Ad.E., Director of the Centre of Genomics and Policy (CGP) at McGill University for his contributions to this document.

Background & Purpose

Empirical evidence suggests that concerns about genetic discrimination (1,2) can influence decision-making and willingness to enroll in research involving genetic testing. Following discussions and representations from advocacy groups and insurers, the government enacted the Genetic Non-Discrimination Act(3) (GNDA), a federal statute, in 2017.

This Canadian law protects genetic data in the context of agreements and contracts. It also contains a more general prohibition against genetic discrimination, but its scope is limited to federally regulated workplaces and services and ethical concerns remain. In reviewing studies that include genetic testing, OCREB board members should also consider other factors specific to each study such as:

- Foreseeable future use of genetic data
- Possibility of data sharing outside Canada
- Privacy and security of the data
- Sensibility of the data
- Vulnerability of the research participants
- Uncertainty as to whether hereditary information falling outside the GNDA’s definition of “genetic data” and “genetic tests” is protected from discriminatory usage.

Overview of the GNDA

The GNDA is a federal statute designed to prohibit and prevent genetic discrimination in Canada. It establishes clear prohibitions regarding the use of genetic testing and genetic test results in the provision of goods and services, the formation or continuation of contracts, and related activities.

The GNDA defines a genetic test as a test that analyzes DNA, RNA or chromosomes for purposes such as predicting disease, assessing risks of vertical transmission, or for monitoring, diagnosis or prognosis.

Core Prohibitions (Sections 3-5)*

* The GNDA also modifies the *Canadian Human Rights Act* to prohibit discrimination based on genetic characteristics of a person. However, the Canadian Human Rights Act only applies to the federal government, First Nations governments, and federally regulated private sectors like banks, broadcasters, and airlines.

Sections 3 to 5 of the GNDA establish three core prohibitions:

- No person may require an individual to undergo a genetic test as a condition of:
 - (a) providing goods or services;
 - (b) entering into or continuing a contract or agreement; or
 - (c) offering or maintaining specific terms or conditions in a contract or agreement.
- No person may require an individual to disclose the results of a genetic test as a condition of engaging in the activities listed above, nor may they refuse to engage in such activities because the individual has refused testing or disclosure.
- No person engaged in these activities may collect, use, or disclose an individual's genetic test results without that individual's written consent.

Exceptions (Section 6)

The prohibitions in sections 3 to 5 do not apply to:

- Health care practitioners (e.g., physicians, pharmacists, or other authorized professionals) providing health services to an individual; or
- Persons conducting medical, pharmaceutical, or scientific research involving an individual who is a participant in that research.

Offences and Penalties (Section 7)

Contravention of sections 3 to 5 constitutes a criminal offence. Penalties may include fines of up to \$1,000,000 or imprisonment for up to five years (on indictment), or lower penalties on summary conviction.

Relevance of the GNDA to OCREB

1. The GNDA does not generally require modifications to the OCREB consent template. In most cases, explicit reference to the GNDA in consent documents may introduce unnecessary complexity or confusion for participants.
2. Where genetic discrimination is identified as a material risk in a study protocol (e.g. studies on hereditary cancer syndromes, germline genetic testing), it may be appropriate to address the protections and limits within the GNDA in participant-facing materials, including the consent. To avoid providing false reassurances, mention of the GNDA should only be made when there is clear indication that the protections from the GNDA apply.
3. Health care professionals⁽⁴⁾ and research team members are best positioned to provide context-specific explanations of the GNDA when needed. This may include explaining that:
 - (a) Individuals cannot be required to undergo genetic testing or disclose results as a condition of accessing goods, services, or contracts;
 - (b) Genetic test results cannot be collected, used, or disclosed in these contexts without written consent and should be voluntarily provided rather than asked for by the insurer;
 - (c) The GNDA's protections are limited to 'genetic tests' and 'genetic test results';
 - (d) Additional protections may arise under applicable privacy legislation governing personal health information, including genetic data.
4. There are grey zones where the application of the GNDA⁵ is uncertain such as:
 - a) other omics test results (e.g. proteomics, polygenic risk scores) that do not fit under the definition of "genetic test" provided for by the law.
 - b) information pertaining to a person's appointments with a geneticists/genetic counsellor and the reason for the appointment.

c) information about surveillance and ongoing appointments associated with an inherited genetic condition.

5. There are instances where the GNDA is unlikely to offer protections such as:

a) information about a person's family history of disease (including genetic conditions).

b) information about the existence of a genetic disease, excluding genetic test results.

6. In cases where the protections of the GNDA are uncertain or unlikely, reviewers should consider whether additional explanation in the consent form is warranted.

References

1. Gopalakrishnan, R., Sam, J., Butkowsky, C., Reble, E., Clausen, M., Rajeziesfahani, S., Sparkes, B., Aguda, V., Aronson, M., Bishop, D., Dawson, L., Eisen, A., Graham, T., Green, J., Mighton, C., Pauling, J., Pavao, C., Pechlivanoglou, P., Remocker, C., Savas, S., ... Bombard, Y. (2024). "Should I Let Them Know I Have This?": Multifaceted Genetic Discrimination and Limited Awareness of Legal Protections among Individuals with Hereditary Cancer Syndromes. *Public health genomics*, 27(1), 240–254. <https://doi.org/10.1159/000542210>
2. Rud, A., Porter, E., Joly, Y., & Uberoi, D. (2026). Addressing genetic discrimination and its stigmatizing effects through human rights. *Journal of community genetics*, 17(1), 18. <https://doi.org/10.1007/s12687-025-00853-9>
3. Genetic Nondiscrimination Act (2017). Retrieved April 19 2026 from: <https://www.parl.ca/DocumentViewer/en/42-1/bill/S-201/royal-assent>
4. Cowan, J. S., Kagedan, B. L., Graham, G. E., Heim-Myers, B., & Bombard, Y. (2022). Health care implications of the Genetic Non-Discrimination Act: Protection for Canadians' genetic information. *Canadian family physician Medecin de famille canadien*, 68(9), 643–646. <https://doi.org/10.46747/cfp.6809643>
5. Fernando, Amy, Emma Kondrup, Katherine Cheung, Diya Uberoi, and Yann Joly. "Still using genetic data? A comparative review of Canadian life insurance application forms before and after the GNDA." *Facets* 9 (2024): 1-10.