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Supreme Court of Canada affirms the Genetic Non-Discrimination Act, weighing autonomy, privacy, and accessibility of insurance

The Supreme Court of Canada (“**SCC**”) recently ruled that Parliament had the power to enact the *Genetic Non-Discrimination Act* (“**GND**A”), and in so doing, make it an offence to require genetic testing, or to share the results of genetic testing (except in limited circumstances) as a precondition to obtaining insurance, among other things.¹ Previously, a five-judge panel of the Quebec Court of Appeal had struck down the law on constitutional grounds.

More specifically, the GND A prohibits companies, including insurers, from requiring genetic testing, or the results of genetic testing, before entering into or continuing a contract with an individual or providing services to an individual.² It also prohibits the collection, use or disclosure of genetic testing results without written, informed consent.³

The Government of Quebec had challenged the constitutionality of the GND A based on the argument that the rules set out therein relate to contracts and the promotion of health, and are therefore beyond Parliament’s jurisdiction. The Attorney General of Canada agreed, as did the Court of Appeal. However, the SCC found that the rules are more properly categorized as criminal in nature since (i) they are in

¹ *Reference re Genetic Non-Discrimination Act*, 2020 SCC 17 [*Ref re GND A*].

² *Genetic Non-Discrimination Act*, SC 2017, c 3, ss 3, 4 [*GND A*].

³ *GND A*, s 5.

the proper form of prohibition and punishment, and (ii) their purpose is to prevent a public harm.

Justice Karakatsanis, in writing for the majority, held that the intention of the prohibitions within the GNDA is to combat genetic discrimination and that fear of negative treatment (including a finding by an insurer that an individual or a family member is uninsurable) may prevent Canadians from undergoing genetic testing, potentially having devastating consequences on their health or the health of the public.⁴

Indeed, testimony before the Standing Committee on Justice and Human Rights revealed that more than a third of families with severely ill children approached to participate in a genetic study declined based on a fear of genetic discrimination.⁵ Besides foregoing a potential explanation or treatment for a debilitating medical condition, the reluctance of individuals to participate in genetic research may also cause Canada to fall behind in important genome research, such as the Human Genome Project.⁶

In addition to the risk of genetic discrimination, the SCC identified that there may be psychological harm to an individual if genetic testing reveals unfavourable characteristics or predispositions that were previously unknown. In addition, sharing genetic testing information may increase the potential for a data breach, resulting in the demand for ransom payments or information being sold for nefarious purposes.

The SCC found that forced genetic testing in particular poses a clear threat to privacy and autonomy, interests which are inextricably linked to the dignity and integrity of individuals and which Parliament has often used its criminal law power to protect.⁷

⁴ *Ref re GNDA, supra* note 1 at para 43.

⁵ Senate, Standing Committee on Human Rights, *Transcript (Evidence) of Proceedings*, 41-2, No 11 (2 October 2014) at 103-104 (Senator Eggleton).

⁶ House of Commons, Standing Committee on Justice and Human Rights, *Evidence*, 42-1, No 37 (24 November 2016) at 1109-1110, 1144 (Dr. Gail Graham).

⁷ *Ref re GNDA, supra* note 1 at paras 82-83, 85.

Impact on Insurers

Part of the argument from the Attorney General of Quebec was that, in pith and substance, the GNDA seeks to regulate the use of genetic information by insurance companies and employers under provincial jurisdiction (and therefore relates primarily to matters properly classified as falling within the provinces' jurisdiction over property and civil rights).

Although such argument was unsuccessful, the SCC did recognize the impact of the decision on insurers. In particular, since insurers (i) are unable to tailor premiums based on genetic test results and (ii) may end up insuring higher risk individuals than they otherwise would have (and thus requiring greater amounts to be paid out), the decision is likely to result in higher premiums for everyone. This may in turn result in accessibility concerns for those with limited financial means, no matter how healthy.

The GNDA does not prohibit an insurer from using the results of a genetic test if such results are obtained lawfully and with consent. However, it's important to note that the GNDA is paramount over any provisions in provincial/territorial legislation to the extent of any operational conflict, meaning that provincial/territorial legislation requiring an individual seeking health or life insurance to disclose all material health information cannot operate to require the disclosure of genetic test results.

Insurers and intermediaries must be cautious to refrain from any activity which may influence an insured's or potential insured's decision to undergo genetic testing or to reveal the results of such testing to the insurer. Violation of the rules set out in the GNDA could lead to a fine of up to \$1 million or imprisonment for up to five years, or both.⁸

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⁸ GNDA, s 7.

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[a cautionary note](#)

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