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Yann Joly, Gratien Dalpé and Miriam Pinkesz

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[See table of contents](#)

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Article abstract

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COMMENTAIRE CRITIQUE / CRITICAL COMMENTARY (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Is Genetic Discrimination Back on the Radar? A Commentary on the Recent Court of Appeal Reference Decision on the Genetic Non-Discrimination Act (GNDA)

Yann Joly¹, Gratien Dalpé¹, Miriam Pinkesz¹**Résumé**

Dans ce commentaire, nous examinons de façon critique la décision de renvoi de la Cour d'appel du Québec à l'effet que la Loi sur la non-discrimination génétique (LNDA) est inconstitutionnelle. En résumé, la Cour a conclu que le gouvernement fédéral a outrepassé ses pouvoirs en matière de droit pénal par l'entremise de la LNDA, car celle-ci n'avait pas d'objet valide en droit pénal. Cette décision a fait l'objet d'une opposition car les groupes de défense des intérêts des Canadiens souffrant de maladies génétiques ou de prédispositions génétiques considéraient la LNDA comme un pas dans la bonne direction et espéraient qu'elle offrirait une protection contre la discrimination génétique. En terminant, nous soutenons que les conséquences de l'avis de la Cour d'appel seront moins graves que ne le prévoient certains groupes de défense. En fait, nous suggérons que cette décision offre une occasion unique de progrès, où les intervenants peuvent faire participer le public et les décideurs à un débat tourné vers l'avenir sur l'utilisation de l'information génétique.

Mots-clés

discrimination génétique, vie privée, soins de santé, engagement des parties prenantes, ELSI

Abstract

In this commentary, we critically review the Quebec Court of Appeal's reference decision to the effect that the *Genetic Non-Discrimination Act* (GNDA) is unconstitutional. In sum, the court held that the federal government exceeded its criminal law power through the GNDA, as the Act did not have a valid criminal law purpose. The decision was met with opposition, as advocacy groups for Canadians suffering from genetic diseases or genetic predispositions viewed the GNDA as a step in the right direction and were hopeful that it would offer protection from genetic discrimination. In closing, we argue that the consequences of the Court of Appeal's opinion will be less dire than anticipated by some advocacy groups. In fact, we suggest that this decision brings about a unique opportunity for progress, where stakeholders can engage the public and policymakers in a forward-looking debate on the use of genetic information.

Keywords

genetic discrimination, privacy, health care, stakeholder engagement, ELSI

On December 21, 2018, the Quebec Court of Appeal rendered an important advisory opinion on the constitutional validity of the *Genetic Non-Discrimination Act* (GNDA) [1]. The GNDA, initially sponsored by Senator Jim Cowan, aims at preventing genetic discrimination by instituting a criminal prohibition against imposing genetic testing or, obtaining the access to or being forced to disclose information obtained through genetic testing with regards to the provision of goods and services. Contravening this prohibition, without the written consent of the individual concerned, constitutes a criminal offense.

Although the GNDA touches upon insurance and employment contracts, the overarching scheme with which Parliament justified the Act, is criminal law, a designated federal power [2, art. 91(27)]. The constitutional division of powers designates certain prerogatives, such as banking, criminal law, and naturalization to the federal government [2, s 91], whereas others, among them, property and civil rights in the province, which include employment and insurance, are delegated provincial powers [2, s 92]. Because the GNDA affects matters under provincial jurisdiction, namely, employment and insurance (through regulating contracts), it must have a subject matter that is under a federal head of power, and only encroaches employment and insurance incidentally [3, paras 36 and 38]. As such, in the case of criminalizing genetic discrimination in insurance and employment, genetic discrimination must constitute an "evil" as per the meaning of criminal law (i.e., found to pose a threat to public peace, order, security, or health in Canada) [4, para 24]. However, the Quebec Court of Appeal concluded that the GNDA does not have a criminal law purpose, and therefore infringes upon provincial jurisdiction.

Preventing genetic discrimination using criminal law?

The above discussion on the GNDA and its potential overstepping of the constitutional division of powers did not go unnoticed by important stakeholders. Notably, the Attorney General of Canada, who would normally represent the federal Parliament in such constitutional cases, shared Quebec's view that the GNDA unjustifiably encroached upon provincial powers. Therefore, he could not represent the Parliament. Under such circumstances, the court may designate an *amicus curiae* (i.e., "friend of the court"), a nonpartisan with an interest in the outcome of the case, that contributes relevant nonpartisan facts or relevant legal arguments, which may otherwise escape considerations by the court [5]. Therefore, when the Quebec government referred to the Court of Appeal the question of the constitutionality of sections 1-7 of the GNDA, the central component of the Act, the appointed *amicus curiae* argued in the place of the federal Attorney General.

The provisions in question specifically criminalize genetic discrimination in insurance and employment by prohibiting any person to require an individual to undergo a genetic test as a condition of providing goods or services to that individual, or of entering into or continuing a contract of agreement, or of offering or continuing specific terms or conditions in a contract or agreement with that individual [6, s 3(1)]. Furthermore, the Act also prohibits any persons to refuse to engage in these activities on the grounds that the individual refused to undergo a genetic test [6, s 3(2)] or refused to disclose the results of a genetic test [6, s 4]. Due to the criminal aspect of infringing the GNDA, violating these stipulations can result in important fines (up to a million dollars) and/or imprisonment of up to 12 months [6, s 7]. Importantly, however, the GNDA includes exceptions to this prohibition for health care practitioners and researchers in the conduct of their activities [6, s 6]. The Act also permits that persons engaged in the prohibited activities can use or disclose the genetic test results of an individual where written consent is provided [6, s 5]. Additionally, the GNDA only applies to genetic tests (as opposed to other types of genetic information),

which are defined as the analysis of DNA, RNA, and chromosomes for the purpose of predicting diseases, the vertical transmission of risks, diagnosis or prognosis [6, s 2].¹

In a unanimous decision, the court determined that the purpose of sections 1-7 is to encourage the use of genetic tests to improve Canadians' health, by "suppressing the fear of some that this information could eventually serve discriminatory purposes" [4, para 11]. According to this interpretation, by reassuring people about their apprehensions concerning genetic testing and potential discrimination, the Act promotes access to personalized medicine. The court therefore concluded that the objective of the GNDA ("to prevent that Canadians refrain from undergoing genetic tests for medical purposes for fear that the results be used without their consent in the context of a contract or of a service") [4, para 9] does not constitute a criminal law object and therefore, the Act is unconstitutional. From a legal standpoint, the opinion of the court on this matter is significant, as it sheds light on the boundaries of the federal government's competence to criminalize the use of genetic information in a field typically considered a provincial head of power, namely, contracts and services.

The Court of Appeal's opinion has the value of a judgement and can be appealed to the Supreme Court of Canada [7, art. 5.1]. As such, sections 1-7 of the GNDA remain in effect, although this may soon change. Disappointed by the decision of the Court of Appeal [7], the Canadian Coalition for Genetic Fairness has since appealed the judgement to the Supreme Court of Canada [8]. Should the Supreme Court render a similar decision to that of the Quebec Court of Appeal, the GNDA would be, for all practical purpose, invalidated. Nevertheless, in the meantime, the Canadian Life and Health Insurance Association Inc. (CLHIA) stated that its members would continue to comply with the GNDA [9].

Would the end of the GNDA open the door to genetic discrimination in Canada?

The answer to this question is more complex than it first appears. In the short term, the invalidation or abrogation of the GNDA would likely raise concerns among patients and carriers of genetic mutations for known monogenic hereditary diseases (diseases associated with a mutation in a single gene), such as Huntington's disease, inherited breast cancers associated with BRCA 1 & 2, and several other rare monogenic disorders.

However, the long-term effects of invalidating the GNDA will likely not amount to the much-dreaded drastic outcome. The Act has important loopholes and raises equity concerns that significantly weaken its capacity to prevent genetic discrimination in most cases. For example, while insurers are not able to impose or request information regarding genetic tests under the GNDA, they could still require information about applicants' family history of disease, an alternative source of genetic information that can impact insurance risk, as they can do for other predictive conditions not associated with known genes, such as cholesterol levels or history of mental illness. The decision to provide protection for some predictive genetic conditions in the GNDA as opposed to others is controversial. Therefore, in the long run, invalidating the GNDA will likely not lead to a "floodgates" situation as it concerns genetic discrimination, because the Act does not provide extensive protection to begin with. Although not directly relevant to the reference decision, this very issue was raised by the Court of Appeal during the hearing, as an attempt to understand the choice of the legislator to include certain (genetic) information as opposed to others. Moreover, the definition of genetic tests used in the Act and its scope of applications (contracts or agreements about the provision of goods and services) further limit the scope of the Act, which the court duly noted [10]. The protection provided by the GNDA is likely not sweeping enough to trigger long-term negative effects in the case it is invalidated.

Importantly, the Quebec Court of Appeal's opinion offers an opportunity to advance on the issue of genetic discrimination and the role of the law and policy-making on this issue.

So, what should we do now?

The current publicity surrounding genetic discrimination and the GNDA sets the stage for stakeholders to engage the public, along with provincial and federal policymakers, in an inclusive and forward-looking debate on the use of genetic information. We propose that, as part of this debate, a successful strategy to address genetic discrimination involves the adoption of a complementary framework of federal and provincial policies in which scientific content (i.e., scope, definitions, sectoral application, responsible authorities, and applicable sanctions) could be determined and updated via easily accessible administrative regulations. These regulations (e.g., administrative decrees, guidelines) would be adopted annually by ministries or agencies having legislative competence in the various areas (employment, insurance, immigration, criminal law) affected by genetic discrimination. Such a mechanism, unlike laws, could resist the test of time, as it is easily modifiable and is thus able to respond quickly to scientific advancements in the field of genetics and emerging social consensus regarding genetic discrimination. It is particularly important to ensure that this framework remains adaptive and flexible, as genetic discrimination is an evolving phenomenon.

Furthermore, this framework should benefit from dynamic and nuanced information campaigns on genetic discrimination and the ideal methods to prevent it, as well as the importance of social solidarity on this matter. An example of such an approach is the [Genetic Discrimination Observatory](#), a communication platform developed to enable collective prevention of genetic discrimination. The platform developed features and activities such as an online forum on genetic discrimination in 2018 and

¹ The Act also modifies the *Canadian Labour Code* in order to prohibit an employer from taking any form of disciplinary action against an employee who refused to take a genetic test or communicate the results of already existing genetic tests [6, s 8]. The Act also modifies the *Canadian Human Rights Act* by adding "genetic characteristics" to the list of prohibited grounds of discrimination [6, s 9]. We note that these provisions were not included in the GNDA reference. However, the application of these protections is limited to the scope of the application of laws in which they are embedded, namely in federal laws.

a report-a-case system where victims of genetic discrimination can securely and confidentially document the circumstances of their case. This information can be used anonymously for statistical and research purposes.

A complementary component to our proposal is to update Canada's obsolete information privacy laws to specifically address and regulate the use of genetic data, especially given the current context of the collection, processing, and transfer of personal data through AI (artificial intelligence), social media, and the Internet. Importantly, in these contexts, individuals' control over personal data is progressively being eroded, and therefore, specially adapted privacy laws may provide much-needed protection. For instance, the growing popularity of social media and genealogy websites or participation in genomic research studies may permit the re-identification of an individual by third-parties [11]. Finally, the growth in government and private DNA databases further supports the development of more stringent privacy oversight and accountability frameworks that promise ample protection against possible misuses of genetic information.

Importantly, however, the governance framework we propose will not be easy to develop, as it requires concerted actions from multiple provincial and federal stakeholders. Nevertheless, it may, in fact, represent the best approach in light of the complex challenges stemming from recent advancements in genetics, in this era of fast-paced science.

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Conflits d'intérêts

Yann Joly est l'auteur d'un rapport d'expert pour le procureur général du Canada dans le renvoi relatif à la loi sur la non-discrimination génétique (2018).

Responsabilités des évaluateurs externes

Les recommandations des évaluateurs externes sont prises en considération de façon sérieuse par les éditeurs et les auteurs dans la préparation des manuscrits pour publication. Toutefois, être nommé comme évaluateurs n'indique pas nécessairement l'approbation de ce manuscrit. Les éditeurs de la *Revue canadienne de bioéthique* assument la responsabilité entière de l'acceptation finale et de la publication d'un article.

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Affiliations

¹ Centre of Genomics and Policy, McGill University, Montreal, Canada

Correspondance / Correspondence: Gratien Dalpé, gratien.dalpe@mcgill.ca

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Conflicts of Interest

Yann Joly was the author of an expert report for the Attorney General of Canada in the Reference concerning the Genetic Non-Discrimination Act (2018).

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