

ERRING IN LAW AND IN FACT: THE SUPREME COURT OF CANADA'S REFERENCE RE GENETIC NON-DISCRIMINATION ACT

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Genetic discrimination has been a public concern for decades but supported by limited evidence. Following a reference from the Quebec government, the Court of Appeal of Quebec considered sections 1 to 7 of the Genetic Non-Discrimination Act (GNDA) were ultra vires of Parliament's criminal jurisdiction (2018). In a 5-4 decision, the Supreme Court of Canada upheld the validity of the GNDA (2020). We contend that the majority's reasoning contains serious errors in law and fact, raising constitutional and scientific concerns. We believe the majority incorrectly determined both the pith and substance of the provisions and the reasoned apprehension of harm standard.

La discrimination génétique, bien qu'elle soit une préoccupation dans l'arène publique depuis des décennies, est pourtant un enjeu peu étayé. Saisie de la question par le gouvernement québécois, la Cour d'appel du Québec a établi que les articles 1 à 7 de la Loi sur la non-discrimination génétique outrepassaient la compétence du Parlement en matière de droit pénal (2018), une décision qui a été contredite par la Cour suprême du Canada à 5 juges contre 4 (2020). Les auteurs soutiennent que le raisonnement des juges majoritaires contient de graves erreurs de droit et de fait, qui soulèvent des problèmes d'ordre constitutionnel et scientifique. Nous estimons que les juges majoritaires ont échoué à dégager l'essence même des dispositions et à satisfaire au critère de la crainte raisonnable de préjudice.

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It is not surprising that elected officials would want to avoid fundamental and controversial issues and focus instead on nominally protecting the public against the highly publicized evils of invidious genetic discrimination. For the time being, at least, it seems that the public is genetically predisposed to let them.

Mark Rothstein, 2007, *Journal of Law, Medicine and Ethics* (JLME)

1. Introduction

The turn of the 21st century brought with it the completion of the Human Genome Project, which represented a major achievement in genomics and further enabled the advent of precision medicine.¹ However, the resulting

¹ Frank Emmert-Streib, Matthias Dehmer & Olli Yli-Harja, “[Lessons from the Human Genome Project: Modesty, Honesty, and Realism](#)” (2017) 8 *Frontier Genetics*, online: <www.frontiersin.org>.

ethical issues have mitigated the enthusiasm surrounding these scientific achievements.² Following a few highly mediated cases of genetic discrimination, some individuals who were offered the opportunity to undertake genetic testing became concerned about being singled out based on their genetic characteristics. Meanwhile, private companies providing DNA and ancestry testing directly to consumers have emerged worldwide as informational and recreational services. These companies, along with large-scale research consortia, helped to push genomic research and the flow of genetic data beyond national boundaries, thus highlighting the need for robust, interoperable data protection frameworks to protect the data of vulnerable individuals. Numerous international organizations, including UNESCO, the Human Genome Organisation, the United Nations Economic and Social Council and some countries, have since adopted positions against genetic discrimination.

The issue of genetic discrimination is intertwined with the notion of genetic exceptionalism. Proponents of genetic exceptionalism consider that genetic information to be especially sensitive and to raise unique challenges for society. Hence, it should be both more severely and explicitly protected than other personal information in our laws.³ Genetic exceptionalism was first formulated as a concept in the 1990's when the direct impact of genes on health was overestimated in comparison to environmental and occupational health factors. Arguments advanced to justify genetic exceptionalism include the fact that genetic information is complex and challenging to interpret, predictive of one's future health, substantially shared with blood relatives and larger population groups, and uniquely identifying when used for forensic purposes, etc. However, counterarguments showing that many of these characteristics would also apply to non-genetic biomarkers have been put forward. Indeed, laws based on genetic exceptionalism may, paradoxically, reinforce stigmas associated with genetic disorders and disregard the underlying existing intersectionality of social and political issues leading to genetic discrimination.⁴

² Albert R Jonsen, *The Birth of Bioethics* (New York: Oxford University Press, 2003).

³ Lori B Andrews, "[Genetic privacy: from the laboratory to the legislature](#)" (1995) 5:3 *Genome Research* 209, online: <genome.cshlp.org>; Michael J Green & Jeffrey R Botkin, "'Genetic exceptionalism' in medicine: clarifying the differences between genetic and nongenetic tests" (2003) 138:7 *Annals Internal Medicine* 571.

⁴ Mark A Rothstein, "[Genetic Exceptionalism & Legislative Pragmatism](#)" (2005) 35:4 *Hastings Center Report* 27, online (pdf): <muse.jhu.edu> [Rothstein]; Thomas H Murray, "[Is Genetic Exceptionalism Past Its Sell-By Date? On Genomic Diaries, Context, and Content](#)" (2019) 19:1 *American J Bioethics* 13, online: <www.tandfonline.com>.

In Canada, the matter of genetic discrimination first came to light in 1991 in a report prepared for the Law Reform Commission of Canada. The report stated that genetic discrimination might occur one day in the contexts of insurance contracts, marriage and reproductive decisions.⁵ In 2010, a Policy Brief presented at a Genomics, Public Policy and Society Meet event hosted by Genome Canada found that there was, at the time, no evidence of the widespread use of genetic testing by insurance companies. It also suggested three avenues for policy reform: 1) Strengthen Existing Human Rights and Privacy Regimes, 2) Introduce a Comprehensive Framework to Govern Genetic Testing Technologies and, 3) Initiate Solutions Specific to the Insurance Sector.⁶ Three decades later, there is still a paucity of documented evidence on this topic. The only major Canadian study was limited to those with a family history of Huntington's disease.⁷ Huntington's is a rare, monogenic and highly penetrant fatal genetic disease, meaning that an individual with an afflicted parent has a 50% chance of inheriting this deadly neurodegenerative condition. In Bombard's study, conducted among 233 asymptomatic subjects (tested or at risk for Huntington's disease), over one third of respondents reported experiences of genetic discrimination, most often in insurance (29.2%), family (15.5%) and social (12.4%) settings.⁸ Anecdotal stories have also surfaced in the lay media, involving cases of discrimination against individual carriers of genes for serious monogenic conditions such as hereditary breast cancer and, again, Huntington's.⁹ Although the evidence of discrimination is rather limited, anxiety over the possibility of discrimination based on genetic testing appears to be widespread in vulnerable populations.¹⁰

⁵ Law Reform Commission of Canada, *Human Dignity and Genetic Heritage*, (Ottawa: Law Reform Commission of Canada, 1991) (prepared by Bartha Maria Knoppers).

⁶ Trudo Lemmens, Daryl Pullman & Rebecca Rodal, "[Revisiting genetic discrimination issues in 2010: policy options for Canada](#)" (2010) Genome Canada, Policy Brief No 2 [Lemmens, Pullman & Rodal].

⁷ Yvonne Bombard et al, "[Perceptions of genetic discrimination among people at risk for Huntington's disease: a cross sectional survey](#)" (2009) 338:7708 *Brit Med J* [Bombard et al, *Perceptions*].

⁸ *Ibid.*

⁹ Shimon Koffler Fogel, "[Genetic Discrimination Means the Choice Between Life and Life Insurance](#)" (12 December 2014), online: *Huffington Post* <www.huffingtonpost.ca>; Kerry Gold, "[How genetic testing can be used against you – and how Bill S-201 could change that](#)" (16 May 2018), online: *The Globe and Mail* <www.theglobeandmail.com>.

¹⁰ Yann Joly et al, *Genetic Discrimination in Quebec: A flexible and proactive approach to address a complex social issue* (Montreal: Centre of Genomics and Policy, 2017).

Following-up on the evidence and concerns raised by Bombard's study, the Huntington Society of Canada started advocating for the adoption of an anti-genetic discrimination law. On April 17th, 2013, following several unsuccessful anti-discrimination bills¹¹ limited to amendments to the *Canadian Human Rights Act*¹² and *Canada Labour Code*,¹³ Liberal Senator James Cowan introduced Bill S-218, *An Act to prohibit and prevent genetic discrimination*, in the Senate.¹⁴ This new bill extended the purview of the earlier bills by adding provisions to criminalize genetic discrimination. A new version of S-218, Bill S-201, was again tabled by Senator Cowan on December 8th, 2015.¹⁵ The Bill was passed by the Senate on April 4, 2016 and was adopted by the House of Commons on March 8, 2017, despite a lack of support from cabinet ministers but with the approval of a majority of both Liberal backbenchers and members of Opposition parties.¹⁶ It received royal assent and entered into force on May 4th, 2017 under the abridged title *Genetic Non-Discrimination Act* ("GNDA").¹⁷

The GNDA makes it a criminal offence for any individual or company to force someone to undergo a genetic test,¹⁸ or force someone to reveal the results of such a test, in order to: a) provide goods or services; b) enter into or continue a contract; or c) offer or continue specific terms

¹¹ Bill C-508, *An Act to amend the Canadian Human Rights Act (genetic characteristics)*, 3rd Sess, 40th Parl (14 April 2010); Bill C-536, *An Act to amend the Canadian Human Rights Act (genetic characteristics)*, 3rd Sess, 40th Parl (14 June 2010); Bill C-445, *An Act to amend the Canadian Human Rights Act (genetic characteristics)*, 2nd Sess, 41st Parl (1 October 2012); Bill C-68, *An Act to amend the Canadian Human Rights Act, the Privacy Act and the Personal Information Protection and Electronic Documents Act*, 2nd Sess, 41st Parl (9 June 2015).

¹² RSC 1985, c H-6.

¹³ RSC 1985, c L-2.

¹⁴ Bill S-218, *An Act to prohibit and prevent genetic discrimination*, 1st Sess, 41st Parl (17 April 2013).

¹⁵ Bill S-201, *An Act to prohibit and prevent genetic discrimination*, 1st Sess, 42nd Parl (8 December 2015). For a legislative summary of this Bill, see Julian Walker, "[Bill S-201, An Act prohibit and prevent genetic discrimination](#)" (Ottawa: Library of Parliament, December 6, 2016), online: <lop.parl.ca>.

¹⁶ John Paul Tasker, "[Liberal backbenchers defy cabinet wishes and vote to enact genetic discrimination law](#)" (8 March 2017), online: *CBC News* <www.cbc.ca>.

¹⁷ SC 2017, c 3 [GNDA]; For a comment of the GNDA, see Kathleen Hammond, "Unnecessary and Redundant? Evaluating Canada's Genetic Non-Discrimination Act, 2017" (2020) 98:3 *Can Bar Rev* 480; We note that since its entry into force three years ago and to the best of our knowledge, there is no case law concerning the provisions of the GNDA, or the new provisions of the *Canadian Human Rights Act* and the *Canada Labour Code* relating to genetic discrimination.

¹⁸ *Ibid*, s 2 (A genetic test is defined in section 2 as "a test that analyzes DNA, RNA or chromosomes for purposes such as the prediction of disease or vertical transmission risks, or monitoring, diagnosis or prognosis").

or conditions for that person.¹⁹ Certain exceptions apply, including for healthcare professionals and researchers in the ambit of their work and research.²⁰ The collection, use or disclosure of the results of a genetic test without the individual's written consent is also forbidden²¹ and accompanied by criminal sanctions. Infractions of GNDA's provisions are punishable by a fine of up to 1,000,000 CAD and/or imprisonment up to 5 years (if convicted on indictment), or by a fine of up to 300,000 CAD and/or imprisonment for up to 12 months (if on summary conviction).²²

Following the enactment of the GNDA, the Government of Quebec maintained that the Parliament of Canada had, by adopting this Act, breached the constitutional division of powers. Although the Parliament used criminal law as an overarching scheme to justify the Act,²³ the Government of Quebec noted that sections 1–7 of the GNDA potentially encroached on provincial powers over property and civil rights,²⁴ including provincial jurisdiction over the insurance and employment sectors. It referred a question to that effect to the Court of Appeal of Quebec in early 2019 under the *Court of Appeal Reference Act* (“CARA”).²⁵ In light of the fact that the Attorney General of Canada did not intend to defend the constitutionality of sections 1–7 of the GNDA,²⁶ the Court of Appeal of Quebec appointed an *amicus curiae* (“friend of the Court”) to ensure a fair representation of this position.²⁷ Taking over from the Huntington Society of Canada, the newly formed Canadian Coalition for Genetic Fairness (“CCGF”) acted as an intervening party in favour of the law. The CCGF argued that the GNDA allows Canadians to make informed life decisions regarding health and reproduction, without fear of genetic discrimination.

¹⁹ *Ibid*, ss 3–4.

²⁰ *Ibid*, s 6.

²¹ *Ibid*, s 5.

²² *Ibid*, s 7.

²³ *Constitution Act, 1867* (UK), 30 & 31 Vict, c 3, s 97(27), reprinted in RSC 1985, Appendix II, No 5 [*Constitution Act, 1867*].

²⁴ *Ibid*, s 92(13).

²⁵ *Court of Appeal Reference Act*, CQLR c R-23 1975.

²⁶ Hélène Buzzetti, “[Ottawa demande aux provinces d’agir contre la discrimination génétique](#)” (2 March 2017), online: *Le Devoir* <www.ledevoir.com>; Yann Joly, Gratien Dalpé & Miriam Pinkesz, “Is Genetic Discrimination Back on the Radar? A Commentary on the Recent Court of Appeal Reference Decision on the Genetic Non-Discrimination Act (GNDA)” (2019) 2:2 *Can J Bioethics* 94; Alanna Crouse, “[Falling Between the Jurisdictions: Genetic Discrimination & the Law](#)” (31 March 2020), online (blog): *McGill Journal of Law and Health* <mjlh.mcgill.ca>.

²⁷ An *amicus curiae* is a nonpartisan individual with an interest in the outcome of the case that can contribute relevant facts or relevant legal arguments, which may otherwise escape considerations by the court, see Anna Wong, “[Evolving role of amicus curiae](#)” online: *Law Times* <www.lawtimesnews.com>.

In its December 21, 2018 decision in the *Reference concerning the Genetic Non-Discrimination Act*,²⁸ the Court of Appeal of Quebec focused on establishing the “pith and substance” (or matter) of the impugned legislation. For a law to be classified as criminal, it must have a valid criminal law object and establish penalties for failure to comply with its prohibitions. A unanimous panel of five judges of this court determined that the GNDA primarily targets insurers and employers.²⁹ It also found that the objective of sections 1–7 of the GNDA is not to prohibit genetic discrimination but rather to encourage the use of genetic tests in order to improve the health of Canadians by suppressing the fear of some that this information could eventually serve discriminatory purposes in the entering of agreements of in the provision of goods and services, particularly insurance and employment contracts.³⁰ Moreover, it considered that these provisions did not have a criminal law purpose³¹ and, thus, were *ultra vires* of Parliament’s criminal jurisdiction.³² It concluded as follows:

It is important to maintain a just and workable balance between the federal and provincial heads of power. A federal [S]tate depends for its very existence on this balance between the central and provincial levels of government. This is why courts, sensitive as they are to the necessity of preserving this balance to ensure Canada’s future, have not been reluctant to invalidate federal legislative provisions inconsistent with the requirements of subsection 91(27) of the *Constitution Act, 1867*. In short, Parliament’s jurisdiction over criminal law cannot be exercised when the object of the legislation does not truly fit within the framework of criminal law. That is clearly the case in this instance.³³

As of right, and in conformity with article 5.1 of the *CARA*, the CCGF appealed the opinion to the Supreme Court of Canada. In the July 20,

²⁸ *Reference Re concerning the Genetic Non-Discrimination Act*, 2018 QCCA 2193 at para 2 [*Re GNDA CA*].

²⁹ *Ibid* at para 8.

³⁰ *Ibid* at para 11.

³¹ *Ibid* at para 24:

There is no ‘real public health evil’ here that would justify the recourse to subsection 91(27) of the *Constitution Act, 1867*. The criminal law object advanced to justify the *Act* is to provide higher quality health care through the promotion of access to genetic tests by suppressing the fear that the results of these tests be used for insurance of employment purposes. This is clearly not a criminal law object. The situation is completely distinguishable from the exercise of federal jurisdiction over criminal law regarding tobacco or illicit drugs, which intrinsically present a threat to public health. That is not the case for genetic tests.

³² *Ibid* at para 25.

³³ *Ibid* at para 26.

2020 *Reference re Genetic Non-Discrimination Act*,³⁴ the Supreme Court reviewed the decision of the Court of Appeal of Quebec. Three of the five majority judges decided in favour of upholding the GNDA, finding that the objective of sections 1 to 7 was indeed to prevent and prohibit discrimination. According to these judges, the Act constituted a valid exercise of Parliament's power to legislate in matters of criminal law, since its prohibitions accompanied by penalties are backed by a criminal law purpose. The two other members of the majority agreed regarding the validity of exercise of Parliament's power over criminal law but considered that the true objective of the Act was to protect health by preventing discriminatory practices in the field of insurance and employment.

In contrast, according to the four dissenting judges, the true aim of the provisions in question was to regulate contracts, particularly contracts of insurance and employment, which ultimately fall within provinces' jurisdiction over property and civil rights. The provisions were in that sense *ultra vires* of the federal government's jurisdiction over criminal law.

The present article will critically review the findings of the Supreme Court of Canada and highlight both the theoretical and more pragmatic impact of this controversial opinion for Canadians. The authors consider that the reasoning of the majority judges in this opinion contains serious errors of law and of fact. Indeed, we conclude that the majority's opinion raises troubling concerns from both constitutional law and scientific standpoints.

2. Erring in Law: Distorting Constitutional Law to Capture Genetics

The question at the heart of this referral is whether or not sections 1–7 of the *Genetic Non-Discrimination Act* constitute a matter of criminal law. The Supreme Court of Canada was tasked with reviewing the opinion of the Court of Appeal of Quebec. In particular, it considered whether sections 91(27) of the *Constitution Act, 1867* empowers Parliament to

³⁴ *Reference Re Genetic Non-Discrimination Act*, 2020 SCC 17 [Re GNDA SCC]. For comments on this decision, see Omar Ha-Redeye, "[Genetic Discrimination is a Health Issue, not a Contracts Issue](#)" (13 July 2020), online: *CanLiiConnects* <www.canliiconnects.org>; Yael Bienenstock et al, "[Genetic discrimination: it's criminal!](#)" (14 July 2020), online: *TORYS LLP* <www.torys.com> [Bienenstock et al]; Jennifer Stoddard & Dara Jospé, "[Genetic Non-Discrimination Act upheld by the Supreme Court of Canada](#)" (22 July 2020), online: *FASKEN* <www.fasken.com>; Sean Griffin, "[Prohibiting Genetic Discrimination: A Valid Criminal Law Subject, According To The Supreme Court Of Canada](#)" (24 July 2020) online: *Langlois lawyers LLP* <www.mondaq.com>; Brandon YY Chen, "[Loi sur la discrimination génétique: Une décision préoccupante de la Cour suprême](#)" (3 August 2020), online: *La Presse+* <mi.lapresse.ca>.

prohibit forcing an individual to take a genetic test or disclose its genetic test results, or to prohibit using an individual's genetic test results without consent, by way of sections 1 to 7 of the GDNA. The response to this question determines whether Parliament enacted the challenged prohibitions for a valid criminal law purpose.

For the majority, Justices Karakatsanis, Abella and Martin found that the impugned sections were designed to prevent genetic discrimination and protect the health of individuals and thereby fell under criminal law, thus allowing the appeal. Concurring with the decision to grant the appeal, Justices Moldaver and Côté disagreed with Karakatsanis, Abella, and Martin concerning the harm that the rules were meant to prevent. They contended that the impugned provisions concern the protection of health by prohibiting conduct that undermines an individuals' control over intimate information revealed by genetic testing.³⁵

Thus, although the majority found that the impugned provisions constitute a legitimate use of criminal law power from the Parliament, there was still substantial disagreement among them over the pith and substance of the law. This disagreement weakens the majority's position according to Justice Kasirer, who spoke for the dissent composed of Chief Justice Wagner and Justices Brown and Rowe. For the dissent, the challenged rules enacted by the Parliament of Canada targeted the field of contracts and attempted to promote health by preventing the misuse of people's genetic information. The impugned provisions regulate insurance and employment contracts, which fall under provincial jurisdiction, and are thus outside the power of Parliament.³⁶ We agree with the minority and believe that the classification of the impugned provisions as a matter of criminal law by the majority constitutes a serious error of law.

A) An inaccurate assessment of the pith and substance of the *Genetic Non-Discrimination Act*

Justice Karakatsanis, writing for Justices Abella and Martin, describes the mischief as a fear of genetic discrimination in the population. This fear could lead many individuals to forego testing that may help them to improve their health while also improving public health.³⁷ She further argues that the pith and substance of the challenged provisions is "*to protect individuals' control over their detailed personal information disclosed by genetic tests, in the broad areas of contracts and the provision of goods and services, in order to address Canadians' fears that their genetic test results*

³⁵ *Re GNDNA SCC*, *supra* note 34 at para 136.

³⁶ *Ibid* at para 154.

³⁷ *Ibid* at paras 43–45.

will be used against them and to prevent discrimination based on that information.”³⁸ Justice Karakatsanis further contends that Parliament is not restricted to the notion of responding to an “evil” in its use of criminal law power.³⁹ The majority applied the requirements derived from the *Margarine Reference*⁴⁰ to help determine if the challenged provisions represent Parliament’s response to a threat of harm toward public order, safety, health, morality or fundamental social values, or to a similar public interest.⁴¹ The approach they used does not focus on whether the law is appropriate or efficient at preventing the harm, but only attempted to determine if the recourse to criminal law constitutes a reasonable option for a particular threat to public interest.⁴² The majority found that the challenged provisions fell under criminal law.

Taking a different view point, Justices Moldaver and Côté from the majority found that “the pith and substance of sections 1 to 7 of the Act is to protect health by prohibiting conducts that undermine individuals’ control over the intimate information revealed by genetic testing.”⁴³ In their opinion, the Parliament of Canada enacted these provisions in order to give individuals the choice to know or not to know about important genetic information concerning their health and that of their families. According to these Justices, the evidence provided before Parliament demonstrated that Canadians were not in a position to make that choice freely.⁴⁴

Dissenting from these views, Justice Kasirer, writing for Justices Wagner, Rowe and Brown, and in agreement with the unanimous decision from the Court of Appeal of Quebec, held that the discriminatory use of genetic information may very well be evil, injurious, or undesirable and, as such, worthy of a criminal ban, but that the impugned provisions of the Act do not include prohibitions targeted at genetic discrimination.⁴⁵ If Parliament had wanted to make a law that aims to protect individuals against genetic discrimination, the scope of GNDA’s provisions would have been broadened beyond “forced [genetic] testing and forced disclosure [of test results].”⁴⁶ On the one hand, the prohibitions in sections 3–5 are limited by the exemption in section 6, which allows disclosure of test results with consent. The penalties in section 7 are also limited by

³⁸ *Ibid* at para 4 [emphasis added].

³⁹ *Ibid* at para 76.

⁴⁰ *Reference Re Validity of Section 5 (a) Dairy Industry Act* (1948), [1949] SCR 1, [1949] 1 DLR 433 [Re *Margarine* cited to SCR].

⁴¹ *Re GNDA SCC*, *supra* note 34 at para 79.

⁴² *Ibid*.

⁴³ *Ibid* at para 111 [emphasis added].

⁴⁴ *Ibid* at para 109.

⁴⁵ *Ibid* at para 159.

⁴⁶ *Ibid* at para 158 [emphasis added].

a narrow, health-based definition⁴⁷ that includes only genetic tests and excludes the provision of other types of information such as family history, or even genetic information, for non-medical uses.⁴⁸ On the other hand, the modifications of the *Canadian Human Rights Act* provided in GNDA section 9 encompass a much broader range of genetic information, since no definition limits the scope of “genetic characteristics.”⁴⁹ In comparison to GNDA sections 1–7, the broad scope of the protection conferred against genetic discrimination in the CHRA, as amended by the GNDA, indicates that preventing genetic discrimination is not the dominant purpose of the contested provisions.

Moreover, Justice Karakatsanis refers to cooperative federalism, an approach based on intergovernmental cooperation and overlap in the exercise of provincial and federal powers, as a justification for the use of criminal law to regulate the insurance sector, a field exclusive to provincial powers.⁵⁰ Yet, the Attorney General of British Columbia argued that this approach, captured by the double aspect and paramountcy doctrines, can too often be invoked to support federal legislation encroaching provincial legislative powers unless meaningful limits to section 91 powers are applied.⁵¹ Justices Deschamps and Lebel, in the *Reference Re Assisted Human Reproduction Act* (hereafter “*AHRA Reference*”), had emphasized that the double aspect applies when the pith and substance of the impugned

⁴⁷ GNDA, *supra* note 17, s 2 (Genetic test means a test that analyzes DNA, RNA or chromosomes for purposes such as the prediction of disease or vertical transmission risks, or monitoring, diagnosis or prognosis).

⁴⁸ *Re GNDA SCC*, *supra* note 34 at para 185 (The scope of this definition excludes genetic tests done for other reasons, for example, to reveal a person’s ancestry or for forensic purposes, or to determine parental lineage or non-disease traits. Genetic tests can obviously indicate other human physical characteristics unrelated to predicting disease and treating medical problems. Some of these characteristics—aspects of physical appearance, for example, or ancestry—might be used as grounds for discrimination or misused in some other manner, but they are not spoken to in the *Act* because they are excluded from the definition of a “genetic test”).

⁴⁹ *Ibid* at para 191.

⁵⁰ *Ibid* at paras 23–25.

⁵¹ *Reference Re Genetic Non-Discrimination Act*, 2020 SCC 17 (Factum of the Intervenor Attorney General for British Columbia at para 17) [FOI BC]. See also Hoi L Kong, “The Federalism Implications of the Assisted Human Reproduction Act Reference” in Trudo Lemmens et al, eds, *Regulating Creation: The Law, Ethics, and Policy of Assisted Human Reproduction* (Toronto: University of Toronto Press, 2017) 44 at 51 [Kong] (The author Hoi L Kong also wrote that the paramountcy doctrine specifies the conditions under which federal and provincial law conflict and mandates that when these conditions obtain, the federal law prevails over the provincial and renders the provincial law inoperative. If applied with restraint, the paramountcy rules, combined with a generously applied double aspect doctrine, permit considerable room for overlapping exercises of legislative power and significant opportunities for intergovernmental cooperation).

provisions distinctly connect with different levels of powers, one under the federal authority and the other under the provincial authority.⁵² However, if the federal impugned provisions significantly affect a sector of activities exclusive to provincial legislatures, these provisions should represent an invalid exercise of the federal powers.⁵³ They argued in favor of avoiding vague characterization approaches and for a rigorous analysis of the pith and substance of the impugned provisions, an exercise that may better assign the challenged provisions under the right head of power, thus avoiding an overflow in the other level of government.⁵⁴

We agree with Justice Kasirer that the dominant purpose of the provisions at issue is to regulate contracts, particularly contracts of insurance and employment, as sections 3–5 are all about contract or agreement or providing goods or services.⁵⁵ We maintain that the majority erred in law in its decision to categorize GNDA sections 1–7 as criminal law under s. 91(27) of the *Constitution Act, 1867*. The appeal should have been dismissed as the challenged provisions were properly categorized by the Court of Appeal of Quebec as being under provincial jurisdiction over property and civil rights conferred by s. 92(13) of the *Constitution Act, 1867*.⁵⁶

B) An inappropriate application of the reasonable apprehension of harm standard

On the issue of whether sections 1–7 of the GNDA are rightly categorized under criminal law power, the majority emphasized that the Court should not freeze the definition of what constitutes a criminal subject matter.⁵⁷ In the majority's opinion, prohibitions of acts that disturb public peace, order, security, health, and morality represent valid examples of different attempts by Parliament to suppress the evil or to safeguard a public interest that is threatened.⁵⁸ Criminal prohibitions enacted by Parliament in relation to tobacco consumption, drugs and adulterated food are all examples in which laws were enacted for the purpose of protecting a public interest such as public safety, health or morality.⁵⁹

⁵² *Reference Re Assisted Human Reproduction Act*, 2010 SCC 61 at para 268 [*Re AHRA*].

⁵³ *Ibid* at para 267.

⁵⁴ Graeme G Mitchell, “[Not a General Regulatory Power: A Comment on Reference re Assisted Human Reproduction Act](#)” (2011) 54 SCLR (2d) 633 at 650–660 [Mitchell].

⁵⁵ *Re GNDA SCC*, *supra* note 34 at para 203.

⁵⁶ *Ibid* at para 272.

⁵⁷ *Ibid* at para 69.

⁵⁸ *Ibid* at para 71.

⁵⁹ *Ibid* at para 73.

To ensure that Parliament has acted within a criminal law jurisdiction,⁶⁰ Justice Karakatsanis applied the reasoned apprehension of harm doctrine, a standard developed in the *AHRA Reference*.⁶¹ However, as noted by Justice Kasirer, Justice Karakatsanis inappropriately applied the dissenting position of former Chief Justice McLachlin in the *AHRA Reference*⁶² when evaluating the reasoned apprehension of harm concerning GNDAs sections 1–7.⁶³ In the *AHRA Reference*, former Chief Justice McLachlin maintained that as long as the harm is reasoned and its legislative action is, in pith and substance, a reasoned response to an apprehended harm, Parliament has all the flexibility to appreciate the amount of harm that characterizes a mischief when justifying the use of criminal law power.⁶⁴ In her evaluation of the reasoned apprehension of harm, Justice Karakatsanis thus deviated from the standard established by the majority of the Court in the *AHRA Reference*.⁶⁵

For the dissent, Justice Kasirer concurred instead with Justices Lebel's and Deschamps' views in the *AHRA Reference*.⁶⁶ He held that Parliament has to clearly identify the harm it seeks to suppress, in this particular case the fear of genetic discrimination, and how the impugned legislation is rationally addressing or preventing that harm.⁶⁷ Justice Kasirer correctly notes that the evidence presented on the record of the GNDAs case almost exclusively comes from parliamentary proceedings,⁶⁸ usually involving a variety of sometimes conflicting opinions.⁶⁹ By contrast, in *RJR-McDonald*,⁷⁰ the threat of serious health issues posed by smoking was supported by a large body of conclusive scientific and medical evidence.⁷¹

We agree with the dissenting judges that the majority erred in law by not properly applying the reasoned apprehension of harm standard. They failed to evaluate the threat posed to public health by the fear of genetic

⁶⁰ *Ibid* at para 75.

⁶¹ *Re AHRA*, *supra* note 52 at paras 50, 55–56, 236–243.

⁶² *Ibid* at paras 45, 50.

⁶³ *Re GNDAs SCC*, *supra* note 34 at para 259.

⁶⁴ *Ibid* at para 78.

⁶⁵ *Ibid* at para 259.

⁶⁶ *Re AHRA*, *supra* note 52 at para 237 (“It must be possible to describe the risk of harm precisely enough that a connection can be established between the apprehended harm and the evil in question”).

⁶⁷ *Ibid*. See Dave Snow, “Blunting the Edge: Federalism, Criminal Law, and the Importance of Legislative History after the *Reference Re Assisted Human Reproduction Act*” (2015) 48:2 UBC L Rev 541 at 586–588.

⁶⁸ *Re AHRA*, *supra* note 52 at paras 41–43, 87–89, 126–128, 141–142.

⁶⁹ *Ibid* at para 170.

⁷⁰ *RJR-MacDonald Inc v Canada (AG)*, [1995] 3 SCR 199, 127 DLR (4th) 1 [*RJR-McDonald* cited to SCR].

⁷¹ *Ibid* at 245–47. *Re GNDAs SCC*, *supra* note 34 at para 245.

discrimination in insurance and employment, as described by sponsors and proponents of the law. In the *AHRA Reference*, Justices Deschamps and Lebel had also warned against categorizing every social, economic and scientific issues as a moral problem that can be dealt with criminal law powers.⁷² The threat to the public interest that Parliament seeks to suppress under criminal law must be real and harmful, meaning that Parliament has to establish a concrete basis of what it is attempting to prevent.⁷³ If it does not need to clearly identify the nature and extent of the threat, Parliament has an unlimited and unfettered power to adopt criminal legislation over a much broader range of matters falling under provincial jurisdiction and can evade effective judicial review.⁷⁴

3. Erring in Fact: Overlooking the Evidence to “Exceptionalize” Genetics

Demonstrating the evidence of harm required to justify the parliament’s power to adopt criminal legislation challenged the Supreme Court judges to assess the legal, ethical and social issues raised by genetic information.

A) The Majority: Hying the evidence of harm

Justice Karakatsanis considered that the risk of harm from the misuse of genetic testing information was substantial and even went as far as saying that:

The potential for genetic test results to reveal **highly personal information** about the individual tested and [the **potential for abuse** of genetic test results and the information they reveal **are**] **immense**.⁷⁵

Furthermore, she described the consequences of genetic discrimination, that is, of people not being tested out of fear of genetic discrimination and “dying of preventable death[s]”⁷⁶ and other related “health consequences,” as “devastating.”⁷⁷ While using slightly different words to describe the situation, the concurring judges, Justices Moldaver and Côté, offered a similar assessment.⁷⁸

⁷² *Re AHRA*, *supra* note 52 at para 239.

⁷³ *Kong*, *supra* note 51 at 50.

⁷⁴ *Mitchell*, *supra* note 54 at 651.

⁷⁵ *Re GND A SCC*, *supra* note 34 at para 88 [emphasis added].

⁷⁶ *Ibid* at para 150.

⁷⁷ *Ibid* at para 126.

⁷⁸ *Ibid* at para 111 (“Parliament had ample evidence before it that this fear was causing grave harm to the health of individuals and their families, and to the public healthcare system as a whole”) [emphasis added].

The conclusion of the two groups forming the majority of the Supreme Court stands in a strong contrast to the assessment of the Court of Appeal of Quebec, which was that: “There is no ‘real public health evil’ here that would justify recourse to subsection 91(27) of the *Constitution Act, 1867*.”⁷⁹ The Court of Appeal went even further by distinguishing genetic testing from other criminal matters, such as tobacco or illegal drugs, which inherently pose a risk to public health. It also added that the file contained no indication that the use or results of genetic testing represented a real issue in any other sector than insurance and employment, apart, maybe, from some matters outside the scope of the law.⁸⁰

The majority’s description and assessment of the risk raised by genetic data is consistent with “genetic exceptionalism,” an approach underlying many restrictive laws regarding genetics.⁸¹ Genetic exceptionalism rests on the notion that genetic information is different, more sensitive, and more susceptible to privacy breaches, than other types of health information. Opponents of genetic exceptionalism argue that many of the concerns raised about genetic information (e.g., its complexity, capacity to predict the occurrence of future diseases, capacity to identify individuals in criminal investigations, etc.) are shared with other types of probabilistic or stigmatizing health information, such as HIV status, cancers, reproductive history and psychiatric conditions, among others.⁸² They also consider that singling out genetics in our laws could create additional problems of justice and fairness, to say nothing of exacerbating the social stigma and “abnormality” of genetic conditions.⁸³

Furthermore, the assessment of the harm to be prevented by the GNDCA should be based on the evidence that was presented to the court of first instance, the Court of Appeal of Quebec. There was a paucity of reliable scientific evidence on file regarding the incidence and consequences of genetic discrimination in Canada, and even less on genetic testing. To date, in Canada, only one large study has focused on genetic discrimination, and only in the specific context of Huntington’s disease,⁸⁴ a genetic condition that is both rare and highly heritable (autosomal dominant), unlike most diseases of genetic etiology. While this study did conclude that genetic discrimination could be a source of anxiety, exclusion and psychological distress for these patients, it did not go so far as to speak

⁷⁹ *Re GNDCA*, *supra* note 28 at para 24.

⁸⁰ *Ibid.*

⁸¹ Yann Joly et al, “Comparative Approaches to Genetic Discrimination: Chasing Shadows?” (2017) 33:5 *Trends in Genetics* 299.

⁸² “[GDO - Frequently Asked Questions](#)”, online: *Genetic Discrimination Observatory (GDO)* <gdo.global>.

⁸³ *Ibid*; Rothstein, *supra* note 4.

⁸⁴ Bombard et al, *Perceptions*, *supra* note 7.

of it being a source of preventable deaths.⁸⁵ The Factum of the Privacy Commissioner of Canada argued for the importance of protecting privacy given the growth of the genetic testing industry but, surprisingly, did not present any empirical evidence to document the effect of privacy breaches or data misuse in this field.⁸⁶ Evidence was also cited from testimonies by the small group of experts, patient advocates, and sponsors of the GNDA who spoke before the House of Commons Standing Committee during the Act's adoption process.⁸⁷ Beyond the rhetoric, these testimonies provided only limited empirical evidence on the incidence and harm of genetic discrimination.

Taken together, the evidence shows that genetic discrimination or, more often, anxiety and distress about being discriminated against, are a problem for a limited number of individuals belonging to families at high risk of developing rare, life threatening genetic conditions. This situation is certainly troubling, as we should be preoccupied with protecting more vulnerable members of our society.

However, interpreting it as proof of an immense risk with devastating consequences seems quite a stretch. Genetics is one type of predictive health data amongst many others, and, apart from certain monogenic conditions, it only contributes in part to common diseases alongside socio-economic, demographic, environmental, and other health factors. Thus, the Supreme Court majority judges made a serious error of fact on this matter.

⁸⁵ *Ibid.*

⁸⁶ *Reference Re Genetic Non-Discrimination Act*, 2020 SCC 17 (Factum of the Intervenor The Privacy Commissioner of Canada).

⁸⁷ Ottawa, Senate of Canada, Standing Senate Committee on Human Rights, 2nd Sess, 41st Parl, *Proceedings of the Standing Senate Committee on Human Rights*, (2 October 2014) (Dr Ronald D. Cohn, from the hospital for sick children (SickKids) in Toronto, did testify that over 33% of 101 families approached by his staff in the context of a research study on pediatric whole-genome sequencing had declined to participate. They were uncomfortable with the possibility that, in the absence of legislative protection, results could make it more difficult to obtain insurance and/or employment. However, insufficient information on the methodology used, including the exact formulation of the question, greatly limits the value of the results from a scientific standpoint. Apart from Dr. Cohn's original testimony to the Standing Senate Committee on Human Rights, these results (on refusal to participate in research because of genetic discrimination) were only briefly mentioned in one line of a scientific study published two years after Dr. Cohn's testimony. Neither additional materials concerning the specific question on genetic discrimination, nor the responses or the statistical analyses were provided in the publication). See also Dimitri J Stavropoulos et al, "[Whole-genome sequencing expands diagnostic utility and improves clinical management in paediatric medicine](#)" (2016) 1:15012 npj Genomic Medicine 15012 at 6, online (pdf): <www.nature.com/articles/npjgenmed201512>.

B) The Minority: Reviewing the evidence with reluctance

The dissenting justices agreed with the Court of Appeal of Quebec's analysis that the pith and substance of the GNDA was to encourage the use of genetic tests as a beneficial health practice. Given this conclusion, they looked at the scientific evidence in a radically different manner, giving it less room in their decision. They also set the bar that needed to be met for evidence higher than the majority, stating that a "real," "well defined threat" (referring to the old expression "evil") needed to be demonstrated in order to constitute a valid subject-matter of criminal law.⁸⁸ The minority's assessment of the threat posed by genetic information is found in a short excerpt towards the end of their reasons:

While the information obtained from a genetic test may be broader in scope, it is not qualitatively different from other medical information, such as information revealed from biopsies, family history, or blood tests, all of which can be obtained and used lawfully under the impugned provisions. Simply because genetic information is relatively novel does not mean that its collection, use, or disclosure constitutes a threat to health. Quite frankly, the collection, use, or disclosure of genetic information is not a threat to Canadians' health by its very nature, unlike tobacco, illicit drugs, or firearms.⁸⁹

As illustrated by this excerpt, the dissent agreed with the Court of Appeal of Quebec's position, both clearly refuting the genetic exceptionalism approach of their colleagues and declining to consider the communication of genetic information as an averred threat. Their position on this matter is that "Parliament has neither articulated a well-defined threat that it intended to target, nor did it provide any evidentiary foundation of such a threat."⁹⁰

What can we understand from this debate between the majority and minority on the risk raised by genetic information in Canada? First, the topic of genetic discrimination is as polarizing as ever. The disagreement within the Canadian Supreme Court reflects a longstanding debate in the media and the research community. The opinion of the majority, of an *immense risk* with devastating consequences, is simply irreconcilable with that of the dissent which speaks of a problem that *may force some* Canadians to make difficult choices, but that is not *per se* different than other types of sensitive health information. The gap between such distinct viewpoints within Canadian society also needs to be bridged. This could be done by collecting and providing additional evidence about genetic

⁸⁸ *Re GNDA SCC*, *supra* note 34 at para 258 [emphasis added].

⁸⁹ *Ibid* at para 248.

⁹⁰ *Ibid* at para 271.

discrimination and its effect in Canada and undertaking an informed public debate to better understand how and why Canadians position themselves on this question.

While the dissent's assessment seems a closer match to the evidence presented, both the majority and dissent of the court seemed to show only a peripheral interest in the (limited) empirical scientific evidence that was presented to them. Such limited interest in seeking a clear understanding of the facts by the Supreme Court does not bode well for future cases involving scientific developments.

4. Conclusion

The errors of law and fact by the majority of Supreme Court make us regret that there is no longer a Judicial Committee of the Privy Council that could, as was once the case, not only set the facts straight and state the law properly, but also, and above all, be the guardian of the autonomy of the provinces within the Canadian federation. The opinion expressed by the Supreme Court of Canada in the *Reference re the Genetic Non-Discrimination Act* has, more than ever before, the potential to upset the constitutional balance of powers when enacting criminal law.

These errors of law, in relation to the qualification and classification of federal legislation dealing with issues of health as relating to criminal law and errors of fact, exemplified by the inaccurate portrayal of genetics, together constitute a harm that could have long-term consequences, as noted by some commentators of the July 10, 2020 opinion:

The majority's expansive interpretation of the Criminal Law power means that Parliament may be able to regulate a whole variety of matters previously considered to be within provincial authority under 'property and civil rights.' So long as the form of the regulation is amendments to the *Criminal Code*, and there is some ostensible relationship with health and/or privacy (or perhaps autonomy or equality), it appears that at least some judges of the Supreme Court will uphold the provision. How and when Parliament chooses to use this power in the future remains to be seen. Predicting the outcome of future decisions regarding the scope of the criminal law power will be difficult in light of the divided Court in this case.⁹¹

Provincial powers on property and civil rights could be severely threatened by the views held by the majority of the Supreme Court. It thus comes as a surprise that Justice Côté, a civil law judge from Québec, sided with the

⁹¹ Bienenstock et al, *supra* note 34 at 4.

majority. She thereby opened the door to future federal encroachment upon matters considered vital for both the preservation of provincial autonomy and the implementation of the federalism principle in Canada. Acting as intervenors, both the Attorney Generals of British Columbia and Saskatchewan had rightly put these arguments before the Supreme Court.⁹²

Another troubling aspect of the judgement involves the treatment of scientific evidence by the Supreme Court. Indeed, the cursive treatment of the facts and limited interest in promoting evidence-based policymaking by the Court is worrying at a time where science plays such an overwhelming role in all aspects of our lives. The green light given by the Court to the *Genetic Non-Discrimination Act* gives a false sense of reassurance to policymakers and patients. It leaves the impression that genetic discrimination will no longer be an issue or creates inequities between different patients and at-risk groups. Yet, some individuals would be protected (those having obtained a positive genetic test result for known monogenic conditions), and others not (those whose common diseases have multiple genetic risk factors, e.g., cancer patients in remission, women at higher risk of developing breast cancer based on family information or physiological exams, or individuals with a family history of type 1 diabetes).

It is always concerning to know that even a small group of Canadians may choose not to undergo genetic testing, which could positively impact their clinical follow-up, or to participate in research, because of concerns related to genetic discrimination. But, the first step to remedy this situation is to better document the problem and prevent it at its root (in this case, the field of insurance). This could be accomplished through voluntary agreements (e.g., codes of conduct, moratoria, an agreement between the Canadian insurers and patient associations), or, if those fail to materialize, through the adoption of specific provincial regulations. Such regulations could be more easily adapted to their specific context and to rapid scientific developments by leaving definitions and prohibited activities to be decided by administrative regulations or annual decrees.

As we enter the era of big data driven medical research and learning healthcare systems, it is clear that a societal debate is long overdue to better understand the concerns and preferences of the Canadian public regarding data protection and the prevention of discrimination.⁹³ However, this

⁹² FOI BC, *supra* note 51; *Reference Re Genetic Non-Discrimination Act*, 2020 SCC 17 (Factum of the Intervenor Attorney General for Saskatchewan).

⁹³ Deborah Hellman, “What Makes Genetic Discrimination Exceptional?” (2003) 29:1 Am J L & Med 77 (U.S. author Deborah Hellman arrived at a similar conclusion

consultation should not be centered exclusively on genetics. Rather, it should consider all biomarkers and tools that are predictive of future health.⁹⁴ Should the empirical data one day warrant a broad prohibition addressing genetics and other predictive health data, a possible human rights approach would be to either explicitly include predictive health data as a prohibited ground of discrimination under physical and mental disabilities, or, simply by adding them at the end of the existing list.⁹⁵ This recourse could be recognized within the prohibitions of discrimination based on physical and mental disability already included in the provincial human rights charters and codes of Canadian provinces and territories that would be broadened by the addition of the prohibition of social attitudes and perceptions as already having the genetic disease.⁹⁶

regarding the need for additional research and to hold public/private discussions. Since this publication, little has changed on these two fronts, especially in Canada).

⁹⁴ For instance, the recent development of proteomics, metabolomics, microbiomics, and epigenetics may soon provide additional layers of information, like genetic information, that may predict an individual's disease risk profile or response to a treatment. Existing normative approaches specifically based on or limited to genetic exceptionalism may not address discrimination based on epigenetics and other types of non-genetic predictive health information. See Charles Dupras et al, "Epigenetic Discrimination: Emerging Applications of Epigenetics Pointing to the Limitations of Policies Against Genetic Discrimination" (2018) 9 *Frontiers in Genetics*, online: <www.frontiersin.org>. See also Mark A Rothstein, "[Epigenetic Exceptionalism: Currents in Contemporary Bioethics](#)" (2013) 41:3 *JL Med & Ethics* 733, online: </journals.sagepub.com>.

⁹⁵ Lemmens, Pullman & Rodal, *supra* note 6.

⁹⁶ *Quebec (Commission des droits de la personne et des droits de la jeunesse) v Montréal (City of); Quebec (Commission des droits de la personne et des droits de la jeunesse) v Boisbriand (City of)*, 2000 SCC 27 at para 76:

[T]he ground 'handicap' must not be confined within a narrow definition that leaves no room for flexibility. Instead of creating an exhaustive definition of this concept, it seems more appropriate to propose a series of guidelines that will facilitate interpretation and, at the same time, allow courts to develop the notion of handicap consistently with various biomedical, social or technological factors. Given both the rapid advances in biomedical technology, and more specifically in genetics, as well as the fact that what is a handicap today may or may not be one tomorrow, an overly narrow definition would not necessarily serve the purpose of the *Charter* in this regard

See *FOI BC*, *supra* note 51 at para 5 [footnotes omitted]:

In British Columbia, discrimination based on the results of genetic testing is treated like discrimination based on any other test that shows elevated risk of negative medical events in the future (for example, a test showing an individual carries the HIV or Hepatitis viruses, or has unusually high levels of cholesterol). Regardless of the scientific etiology of the risk, discrimination based on a statistical or probabilistic propensity to develop a medical condition in future is discrimination based on disability. B.C.'s *Human Rights Code* bans discrimination based on mental or physical disability either in access to goods

Finally, on a hopeful note, it bears noting that genetic testing is now entering the clinic as part of the diagnostic standard of care. This 'normalization' of genetics in the understanding of common diseases would foster its recognition as another type of predictive health information (e.g., high cholesterol, glucose level, calcium) and so could serve to remove the stigma created by genetic exceptionalism, which considers genetic testing results as having pre-determined 'devastating health consequences'.

or services or in employment, and genetic discrimination within the meaning of the *Act* is caught in this wider prohibition.