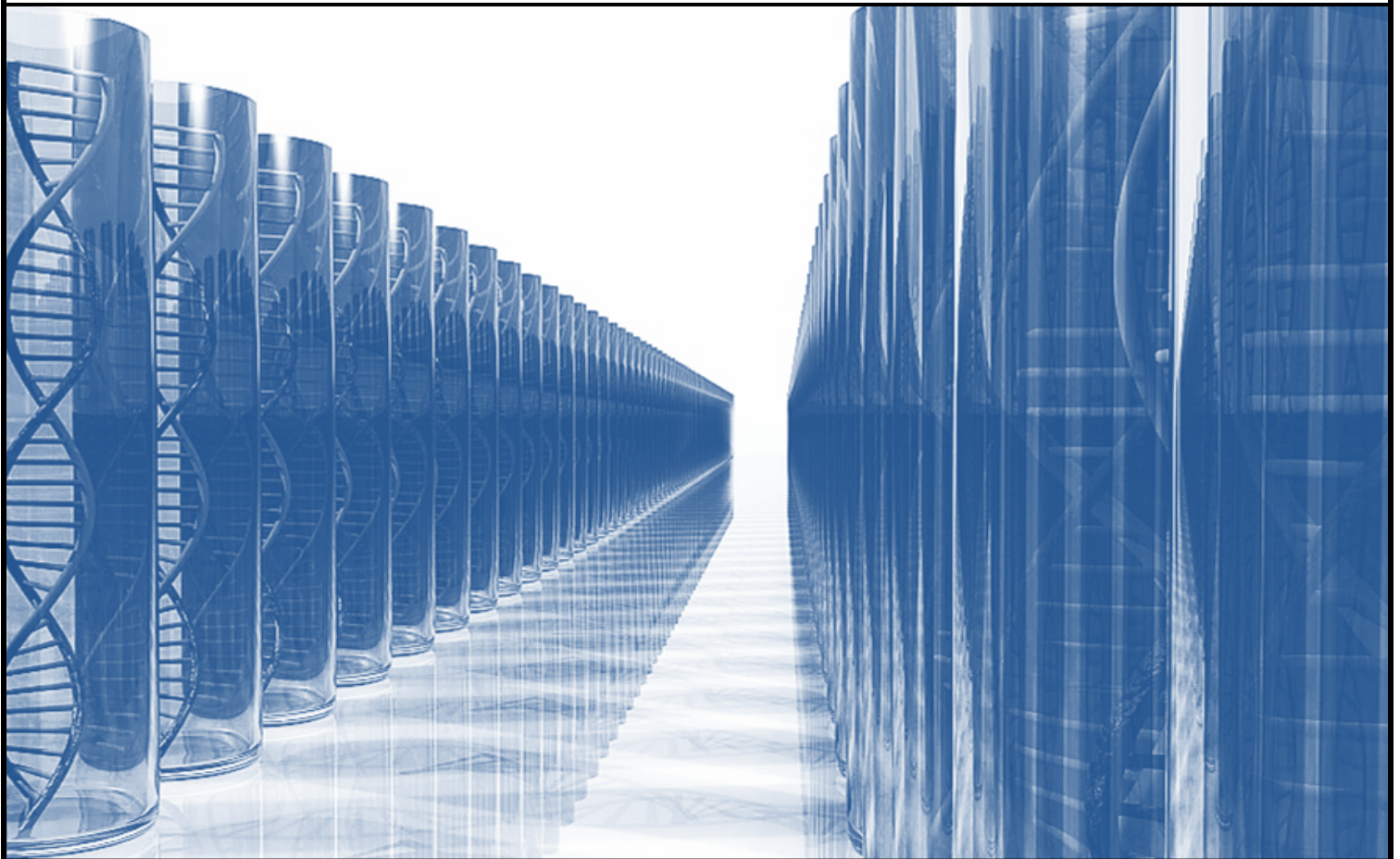


# GENETIC DISCRIMINATION IN QUÉBEC

A FLEXIBLE AND PROACTIVE APPROACH TO ADDRESS A COMPLEX SOCIAL ISSUE

– POLICY BRIEF –



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CENTRE OF GENOMICS AND POLICY (CGP)

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## **Génome Québec**

Established in 2000, Génome Québec is a private, non-profit organization with its headquarters in Montréal. Its mission is to catalyze the development and excellence of genomics research and promote its integration and democratization. Génome Québec is recognized for its assertive leadership in promoting an optimal environment conducive to the advancement of genomics research and the integration of its benefits into priority sectors for Québec. A strong culture of ethics drives its mission, providing assurance that research will be conducted within ethical guidelines acceptable to society at large.

To promote a better understanding and support decision making regarding the complex issues raised by genetic discrimination, Génome Québec asked the Centre of Genomics and Policy to produce a Policy Brief on the subject. This document is the result of analysis and research conducted by the authors of the CGP. The views expressed herein do not necessarily reflect those of Génome Québec.

## **Centre of Genomics and Policy (CGP)**

An integral part of the McGill University and Génome Québec Innovation Centre, the Centre of Genomics and Policy (CGP) is at the crossroads of the legal, medical and public policy fields. Within a multidisciplinary perspective and in cooperation with national and international partners, the CGP analyzes the ethical, legal and social norms that influence the many aspects involved in health prevention, protection and promotion. The CGP is currently conducting research on the ethical and legal issues involved in several areas of genomics research, including personalized health, pediatrics, cancer research, gene therapy, biobanks (population genetics) and the impact of new technologies on privacy.

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## **Executive Summary**

In recent years, genetic research has led to the creation of screening tests capable of predicting a person's risk for various diseases, including breast cancer and Alzheimer's, or an individual's response to a given drug. In addition, the latest high-throughput sequencing technologies can now be used to sequence the whole genome of a human being. Genetic tests and technologies are at the forefront of a new type of personalized medicine, whose purpose is to treat patients with greater precision based on their genetic, clinical and environmental data. The recent advent of techniques used to transfer mitochondrial DNA and edit the genome suggests that in the not-so-distant future, it may be possible to modify the genome of individuals at varying stages of development to protect them from disease. The promises of genetics in health care, however, remain to be demonstrated through further research. Genetic information can also be used outside the medical context. This is the case, for example, with genealogical studies used to demonstrate biological lineage among family members or DNA testing done to prove the identity of a suspect during criminal investigations. The use of genetic information outside the context of medicine or medical research can, therefore, be a valuable asset on condition that it respects the values and fundamental rights of our society.

Genetic discrimination occurs when a person is excessively profiled or treated negatively based on genetic characteristics (suspected or proven). As with other forms of discrimination involving gender, ethnicity or disability, genetic discrimination can be a source of exclusion. It can limit a person's social and professional opportunities. When this is the case, a person's rights and freedoms may be compromised. One thing is certain, however. Genetic discrimination leads to the psychological distress of those involved.

At the moment, no major empirical study evaluating the extent of genetic discrimination in Québec has been conducted. In Canada, too, there is too little data on the subject, which further complicates matters in terms of our understanding of the problem at the provincial level. Moreover, the studies available deal with specific situations, such as life insurance coverage for people at risk of developing Huntington's disease. No other evidence offers compelling data confirming the existence of widespread genetic discrimination. The fear of being the target of discriminatory practices based on genetics is, however, pervasive in Canada. It stands to reason that this reflects the views of people in Québec as well.

The purpose of this Policy Brief is to provide policymakers with recent and contextualized data on genetic discrimination and offer recommendations for follow-up to help them develop a Québec prevention strategy.

### **Summary of Recommendations to Policymakers:**

1. That the Québec government wait to have sufficient information for sound decision making before determining whether or not provincial legislation on genetic discrimination is necessary. (p. 9).
2. That the Québec government allocate the resources needed to conduct comprehensive legal analyses to determine the strengths and weaknesses of the Canadian Genetic Non-Discrimination Act. (p. 9).
3. That the Québec government appoint and fund a provincial organization whose role would be to inform the public, monitor practices and field complaints on genetic discrimination. (p. 9).
4. That the Québec government set up an advisory committee of independent experts to monitor in real time the incidence and consequences of genetic discrimination in Québec and prepare a summary report on the matter (p. 12).
5. That the Québec government allocate the necessary resources to conduct a survey among the Québec public regarding genetic discrimination. (p.12).
6. That the Québec government request further comparative research on the effectiveness of genetic discrimination protection models and public policies that exist around the world. (p.15).
7. That the Québec government fund the development of effective and clear communication tools on genetic discrimination and the ways to prevent it. (p.15).

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## **A - Scientific, Ethical and Legal Context**

### **Genetic Research: A Source of New Opportunities**

The use of genetic information to diagnose genetic diseases or predict the risk of developing such diseases in the future is likely to interest third parties other than physicians and genetic researchers. For instance, when reliable genetic information has significant implications for an individual's current or future health, insurers have an interest in using this information, along with other health data,<sup>1</sup> in order to determine the applicant's level of risk for the company. Employers may also wish to use genetic information pertaining to a candidate's future health to avoid hiring someone who may have a high rate of absence due to illness. At the moment, the number of highly reliable diagnostic or predictive genetic tests to assess serious health issues remains very limited. Finally, the recent development of genome-editing technology raises many longer-term concerns on the possibility of a future social order where people would be treated differently based on their willingness or ability to pay to have their genome, or that of their children, improved.

Detecting a combination of genetic markers can often be enough to differentiate a person from a group and even provide information on certain biological or physical characteristics. Genetic information can also be used outside the medical context for genealogical studies to determine biological kinship among individuals. In addition, it can be used to help identify criminals with DNA evidence. To date, mandatory DNA testing was used to establish the genetic profiles of 352,244 suspected or convicted criminals in Canada (RCMP, 2017). These profiles are stored at the National DNA Data Bank. They are used to facilitate the identification of suspects during police investigations by comparing their genetic profile with those in the database, which contains crime scene DNA.

The use of genetic information in areas other than medicine or medical research can meet important needs. It can be said, for instance, that the National DNA Data Bank was created to protect the public. Yet if the legislative framework governing the non-medical use of genetic information is inadequate or if the collection or use of the information does not align with social values and basic human rights, then discrimination may arise.

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<sup>1</sup> The *Québec Charter of Human Rights and Freedoms*, QLR, c. 12, s. 20.1 already recognizes the interest insurers have in using an individual's health data for risk determination purposes in the context of insurance contracts. However, this section of the Charter does not specifically mention genetic information.

## **Ethical and Social Dimensions of Genetic Discrimination**

Genetic discrimination (GD) occurs when a person is excessively profiled or treated negatively based on actual or suspected genetic characteristics.<sup>2</sup> As with discrimination based on gender, ethnicity or disability, GD can be a source of exclusion and lead to the loss of social and professional opportunities. It is also directly associated with psychological distress. Some evidence suggests that GD disproportionately impacts vulnerable or marginalized groups: people with hereditary or orphan diseases, disabled persons, visible minorities, including Native Peoples, immigrants, prisoners, intersex people, etc. (Bombard et al, 2009; Granados Moreno et al, 2017). In addition, the fear of GD may cause some to forego medically required genetic testing or refuse to participate in genetic research.

Canadians are already familiar with many of the ethical values and fundamental rights involved in the debate on GD, for instance, human dignity, the right to equality, the fight against social inclusion and principles of fairness and privacy. Less well known by the public is the principle of *genetic exceptionalism*, which also plays a leading role in the debate. This controversial principle states that due to its complex, rich and predictive nature and its ability to identify individuals and their family connections, genetic information raises unique challenges and requires special legislative protection. Proponents of legislation to prevent GD often use the principle of genetic exceptionalism when making their case (Rothstien, 2005). But depicting genetic information as special or more vulnerable on ethical grounds can mean ignoring the fact that it shares many similarities with other types of medical information (e.g., predictive tests, family history, HIV status, etc.). In addition, granting genetic information special legal status can further stigmatize people or communities on the basis of their particular genetic characteristics.

### ***Genetic Non-Discrimination Act (S-201)***

The *Genetic Non-Discrimination Act (S-201)* (hereinafter “the Act”) was adopted in 2017 by the House of Commons and received Royal Assent. The Act makes it a criminal offence to require individuals to undergo a genetic test or disclose the results of a genetic test as a condition of providing them with goods or services, entering into or continuing a contract or agreement with them, or offering them special conditions in the contract or agreement. Exceptions are provided for the use of genetic test results by health practitioners and researchers. The Act also amends the *Canada Labour Code* to

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<sup>2</sup> We have opted for a broad and social definition of genetic discrimination. This “social” definition should be distinguished from the more restrictive legal protection from certain forms of discrimination afforded by Canadian human right laws. In fact, Canadian legislation in this area recognizes only a very limited number of potentially problematic grounds for discrimination.

prevent federal employers from requiring their employees to undergo genetic tests or disclosing the results of such tests. Finally, it amends the *Canadian Human Right Act* to prohibit, at the federal level, discrimination on the ground of genetic characteristics (Walker, 2014).

It was modelled on European laws (e.g., France, Belgium, Germany) developed some fifteen years ago primarily to prevent GD in life insurance and employment. The Act defines a genetic test 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<sup>3</sup>.” The definition includes some, but not all tests generated by new genetic-derived disciplines and offered as part of personalized medicine.<sup>4</sup> It also excludes information on family diseases (including hereditary genetic diseases) and predictive health information from non-genetic tests (e.g., cholesterol level).

Some experts question the constitutionality of the Act, since its purpose is not truly criminal in nature, hence outside the jurisdiction of the federal government. In their view, this legislation may encroach upon provincial areas of responsibility, which include property and civil rights, since it deals with the regulation of good and services, contract law and, more generally, health. Other experts believe that the Act is a legitimate use of federal power (Walker, 2014). Given the issue raised by the Act’s constitutionality, on July 7, 2017, the Québec government filed a reference before the Court of Appeal in Québec for an opinion on whether section 1 to 7 of the Act are *ultra vires* - beyond the power of the federal government in the area of criminal law.

The Act also raises important questions regarding fairness. For example, why provide specific legislative safeguards for carriers of genetic mutations, but not for people whose disease is in remission or those who have undergone predictive, yet non-genetic health testing. Moreover, the possibility of collecting or using genetic results upon obtaining the consent of individuals (section 5 and 8 of the Act) significantly weakens the protection provided since individuals with a family history of genetic disease(s) may feel obligated to submit genetic test results to offset the negative impact of their history. People with a “good genetic profile” may also choose to submit this information to an insurer in the hopes of obtaining preferential treatment compared to other consumers.

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<sup>3</sup> *Genetic Non-Discrimination Act (S-201)* – Definitions: <http://laws-lois.justice.gc.ca/eng/acts/G-2.5/page-1.html>

<sup>4</sup> Examples include fast-growing fields of study, such as epigenetics, proteomics, metabolomics. Moreover, discrimination could result from the use (or non-use) of genome-editing technologies, for instance the new Crispr-Cas9 technique not likely be covered by the Act, which applies the more restrictive notion of “genetic test.”



**Recommendation 1: That before determining whether or not provincial legislation on genetic discrimination is necessary, the Québec government wait for** a) the opinion of the Court of Appeal on the constitutionality of the Genetic Non-Discrimination Act and b) the results of studies, surveys and tracking measures recommended in this document.

**Recommendation 2: That the Québec government allocate the resources needed to conduct comprehensive legal analyses to determine the strengths and weaknesses of the Canadian Genetic Non-Discrimination Act.** The issues of a) constitutionality, b) equality among citizens and c) actual protection granted by the Act must be given priority.

**Recommendation 3: That the Québec government appoint and adequately fund an independent organization,** such as the Commission des droits de la personne et des droits de la jeunesse, to a) **inform the Québec public** on the safeguards available, b) **monitor practices** in high-risk sectors, c) **field complaints** and answer questions from the public.

## **B - Review of Empirical Evidence on Genetic Discrimination**

While still few in number, some studies have recently shed light on genetic discrimination, the concerns it raises among the public and the impact of these concerns on people's health and on research conducted using human subjects.

### **Genetic Discrimination Around the World**

So far, research on GD has focused primarily on the differential treatment of at-risk individuals by insurance companies and the impact of such treatment. In 2013, a team from the CGP led by Yann Joly (McGill University) presented findings from a systematic review of the evidence on the subject published between 1991 and 2012 (Joly et al, 2013). Of the 33 empirical studies reviewed, 14 (42%) concluded that GD is indeed real and concerns raised are legitimate; 16 (48%) reported that the incidence of GD is relatively rare and found very little actual impact on access to insurance and 3 (9%) found no evidence of GD. For the most part, these studies, which were conducted primarily in the United States, Canada, United Kingdom and Australia, pertained to the experiences and perceptions of patients at a high risk for single-gene diseases, such as Huntington's disease, hereditary breast and ovarian cancer and familial hypercholesterolemia. According to Joly et al (2013), the small scope and heterogeneity of the samples analyzed in most of the studies, the indication of the incidents being accidental rather than voluntary and the many methodological shortcomings of the studies prevent us from drawing clear conclusions on the extent of the problem

and existence of discriminatory practices by insurers. In the case of Huntington's disease, however, research evidence of GD is particularly robust and compelling (Bombard et al, 2009; Erwin et al, 2010; Otlowski et al, 2012).

In Canada, the largest empirical studies to date have been led by Yvonne Bombard (University of Toronto) in the context of Huntington's disease. In one study conducted among 233 asymptomatic subjects (tested or at risk), over one third of respondents reported experiences of GD most often in insurance (29.2%), family (15.5%) and social (12.4%) settings (Bombard et al, 2009). As is the case in the majority of international studies, GD by employers is rarely experienced (6.9%) by people tested or at risk for Huntington's disease. As mentioned by Lemmens et al (2010) a few years ago in a policy brief prepared for Genome Canada, there are two significant weaknesses in the empirical data on GD in Canada: (1) the thin line between discrimination based on medical family history versus a positive genetic test and (2) the subjective nature of self-reported cases of discrimination (Nicholls et al, 2014). Moreover, no study specific to Québec has yet presented a comprehensive portrait of GD in the province.

### **Concerns About Genetic Discrimination: Extent, Origins and Consequences**

Despite the small number of studies that measure the extent of GD, other research has focused on public anxiety surrounding the possibility of GD following a positive genetic test. While these studies do not address the actual incidence of GD, they nonetheless shed light on the perceived risk of genetic discrimination among those surveyed. They also help to explain certain people's apprehension about genetic tests and anticipate the impact of this fear.

A systematic review by Wauters & Van Hoyweghen (2016) reported that the level of concern about the potential for GD is relatively high and widespread around the world. It varies based on the genetic condition studied and is more common in the insurance setting and interpersonal relationships. In most countries surveyed, the risk of GD by employers does not appear to generate the same level of anxiety. In the United States, however, the fear of job-related GD is greater, possibly due to the employer-sponsored health coverage in that country. According to Allain et al (2012), GD is a cause for concern for nearly 30% of people who have considered undergoing a genetic test for breast or ovarian cancer in the U.S. By way of comparison, 61% of participants worried about genetic discrimination by an insurer. In 20% of cases, the fear of GD influenced the respondents' decision not to go ahead with this genetic test. A few years prior, the negative impact of public fear of GD was also observed by Keogh et al, (2009) in the Australasian Colorectal Cancer Family Study. The proportion of participants who refused a genetic test made available to them was at least twice as high among

people who were informed of the risk of GD. It is becoming increasingly obvious that the fear of GD is likely to deprive patients of the potential benefits of genetic testing specific to their situation (Wauters & Van Hoyweghen, 2016).

In Canada, public concern about the possibility of GD was reported to be “moderate but widespread” in a 2013 survey on Canadians and Privacy (Phoenix Strategic Perspectives Inc., 2013). More than half of survey respondents expressed concern about having to undergo a genetic test recommended by their physician, if an insurer or employer could then access the information. Among them, 70% would even forego the genetic test prescribed. A study on Huntington’s disease found that up to 86% of participants were concerned about GD (Bombard et al, 2012). During a genome research study in pediatrics, no less than 35% of families reported not wanting to know the study results to avoid obtaining information that could compromise their future access to insurance coverage or employment (Stavropoulos et al, 2016). This reluctance could be explained in part by the ambiguity of the questions (often broad and unclear), in the application forms from Canadian insurers (Ngueng Feze & Joly, 2014).

In response to the real and/or perceived risk of GD and its potential negative implications, the Canadian Civil Liberties Association (CCLA) recently called on the Canadian government to strengthen its privacy protection mechanisms and fight unjustified discrimination not only to protect Canadians from the presumed economic interests of insurers and employers, but also in the area of immigration laws and policies. According to the CCLA, whose recommendation is based on complaints received in recent years, criminal investigations and the immigration process can at times be streamlined by obtaining, disclosing and/or making questionable use of genetic information from vulnerable groups, such as First Nations and migrant workers (CCLA, 2016). Furthermore, immigrants are believed to be at risk for GD when applying for family reunification in a host country that requires DNA evidence to confirm biological relationships (Joly et al, 2017).

Given the lack of empirical data on GD in Québec, a team from the CGP recently launched a pilot study in partnership with Dr. Jacques Simard of the research centre at the CHU de Québec on the views of women and decision makers regarding genetic testing for breast cancer risk (Dalpé et al, 2017, in press). Study results indicate considerable reluctance by Québec women to undergo the test for fear of discrimination by insurers. Following interviews with decision makers, the study also suggests that the interest of insurers for genetic information is very real. In light of this study, it is clear – as recently argued by Lane et al, (2015) – that better tools and conduct guidelines must be developed to help health professionals better communicate with patients on the risk of GD.

**Recommendation 4: That the Québec government set up an advisory committee of independent experts to monitor the incidence and consequences of genetic discrimination in Québec.** The role of this advisory committee would be to study current cases of genetic discrimination in Québec, produce a comprehensive portrait of the local situation and, in the medium term, issue a summary report including follow-up recommendations for the government.

**Recommendation 5: That the Québec government allocate the necessary resources to conduct surveys among the Québec public regarding genetic discrimination.** These surveys will help to a) identify the extent of the problem and describe reported cases in Québec and b) evaluate the knowledge and concerns of the Québec public with regard to genetic discrimination.

## **C - Existing Normative Approaches to Genetic Discrimination**

### **A Review of International Approaches**

The CGP has carried out many studies on the normative approaches used around the world to prevent GD (Lemmens et al, 2004; Joly et al, 2010; Ngueng-Feze & Joly, 2014; Joly et al, 2017; Granados-Moreno et al, 2017). What follows is a comparative summary of the various approaches currently applied in different regions and countries (see also the map in Appendix 1).

As early as 1997, UNESCO took position against GD in its *Universal Declaration on the Human Genome and Human Rights* (UNESCO, 1997). Following the Declaration, international consensus on the need to prevent GD in domestic law arose among international organizations (UNESCO, 2005). In Europe, the *Charter of Fundamental Rights of the European Union* (2012) and the *Convention on Human Rights and Biomedicine* (1997), influenced many European countries to adopt legislation against GD. The Council of Europe (2016) even recommended that insurers not be allowed to request genetic tests or use the results of genetic tests and applied some of its conclusions to all predictive health information, including non-genetic information. The majority of European countries have adopted an approach based on genetic exceptionalism (granting special protection from GD by recognizing the special, more sensitive nature of genetic information). The United Kingdom opted for a moratorium; a flexible, provisional approach based on an agreement between the government and the Association of British Insurers (ABI). Implemented in 2001 and reviewed periodically, the moratorium prohibits members of the ABI from using genetic test results unless they have been previously approved by the government and independent experts.<sup>5</sup>

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<sup>5</sup> At the moment, the only pre-approved test is the one for Huntington's disease. The test is only pre-approved for insurance contracts above a certain financial limit.

North America: In the United States, the issue of GD is particularly controversial given the lack of a universal health care system. Through four pieces of legislation - the *American Disabilities Act* (1990), *Health Insurance Portability and Accountability Act* (1996), *Genetic Information Nondiscrimination Act* (GINA) (2008), and *Affordable Care Act* (2010), the U.S. federal government has established a national threshold guaranteeing a minimum of protection against GD. Additional protection in the area of life insurance not covered at the federal level is available in certain states (Prince & Roche, 2014). Mexico has amended two of its federal laws by adding general prohibitions against genetic discrimination based on genetic traits (*Federal Law to Prevent and Eliminate Discrimination*, 2003—amended in 2014; *General Healthcare Law*, 1984—amended in 2015).

Asia and Oceania: In Australia, where many research studies have been done on GD (Barlow-Stewart et al, 2009), the *Disability Discrimination Act* (1992) was adapted to include discrimination based on the genetic predisposition to disability. Its application, however, is greatly limited by exceptions to the law. New Zealand does not have specific legislation on GD, but insurers have adopted guidelines on genetic testing to inform the public of their practices in this area (ISIA, 2000).

Asia: Even if genetics is growing at an accelerated rate in this region of the world, only South Korea (*Korean Bioethics and Biosafety Act*, 2013) and Taiwan (*Personal Information Act*, 2012) have adopted legislation against GD. Middle East: Israel is the only Middle Eastern country to have adopted a prohibitive, sector-specific approach to GD for the insurance and employment settings (*Genetic Information Law*, 2000).

In South America, Chile has a national law based on genetic exceptionalism, while Argentina has rather adopted local legislation against GD in the insurance context for populated regions (Buenos Aires and the province of Cordoba). In Africa, Malawi is the only country to offer legal protection against GD through ethical recommendations sanctioned by the *Science and Technology Act No. 16 of 2003* (Malawi National Health Science Research Committee, 2003). In most African countries, GD is not considered a pressing social issue given that genetic testing is not yet an integral part of the health and biometric fields.

### **Studies on the Effectiveness of Each Approach**

It is interesting to note that the development of many public policies on GD - particularly in Europe - was not followed by studies aiming to measure the effectiveness of the policies at reducing GD or meeting the more modest goal of reducing public anxiety about the risk for discrimination. Surveys on public perception of genetics indicate that despite the adoption of non-discrimination laws, Europeans still feel a degree of apprehension about the potential use of genetic data by third parties,

such as insurers and government agencies. In addition, this fear continues to have a negative impact on participation in research projects, including genetic biobanks (Gaskell et al, 2011). One of the only studies on DG conducted after the adoption of legislation involved Dutch families at risk for hypertrophic cardiomyopathy. It confirmed these findings. The study authors concluded that the enactment of the Dutch non-discrimination legislation did not: “appear to alleviate the concerns of genetic discrimination” (Geelen et al, 2012). Again in the Netherlands, a 2008 agreement among the Association of Insurers, patient associations and professional associations led to the adoption of guidelines on mortality and morbidity risk determination due to familial hypercholesterolemia. According to the 2012 tracking study, these guidelines produced positive results by facilitating access to life insurance by this group and helping to reduce the negative perception about GD. For the most part, the guidelines have also been appropriately applied by insurers (Huijen et al, 2012). This indicates that targeted extra-judicial solutions may sometimes generate better results compared to legislative approaches. Legislative may not be as readily accessible to victims of discrimination or widely known by the public and may lack the flexibility to adapt to scientific advances in the rapidly changing field of genetics.

This mitigated opinion on the success of legislation-based responses to GD is also supported by American studies on *GINA*, the non-discrimination law currently in effect in the U.S.(Steck et al, 2016). The studies indicate that the vast majority of Americans do not know that *GINA* exists and report that public anxiety about GD has not significantly diminished since the enactment of the law. Even among physicians and patient rights advocacy groups, nearly 50% of those surveyed had no idea that *GINA* existed many years after its enactment. Genetic counsellors were the only category of survey participants considered to be “in the know” about the Act. The small number of genetic counsellors and the limited access to them by low-income patients and those living outside large cities make it difficult to properly share information about the Act to those affected. These findings demonstrate the importance of launching a well-orchestrated public information campaign with the enactment of non-discrimination laws, given that GD is a complex issue that needs to be clearly explained to the public.

While limited in number, European and American studies tend to indicate the importance of clear information practices and user-friendly access points to share with the public information on available protections and resources. They also point to the limitations of substantive laws when it comes to addressing the challenges raised by GD, indicating the need to consider the various policy options before opting for the legislative avenue.

**Recommendation 6: That the Québec government request further comparative research on the effectiveness of genetic discrimination protection models and public policies that exist around the world.** The study should focus on: 1) the effectiveness of strictly legal solutions, b) the problems associated with applying a law in the rapidly changing field of biotechnology, c) the sectors of activity often overlooked and more vulnerable groups and d) the accessibility of available remedies.

**Recommendation 7: That the Québec government fund the development of effective communication tools on genetic knowledge and possible remedies available in Québec in cases of genetic discrimination.** A clear, dynamic information campaign would help launch a constructive public debate on the ethical, social and legal challenges of genetics.

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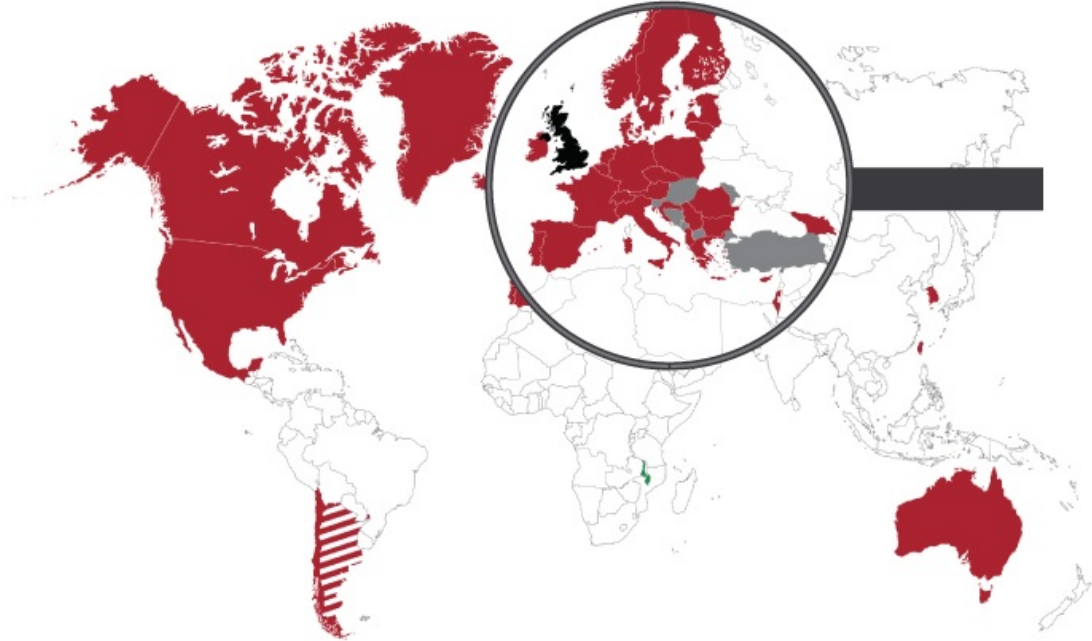
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

# Appendix 1: Worldwide Normative Approaches to Address Genetic Discrimination

Source: Normative Approaches to Address Genetic Discrimination : Placebo or Panacea?

Joly et al SSRN (2017)



-  Countries with laws specifically addressing GD
-  Countries that have ratified the European Convention on Human Rights and Biomedicine but not yet adopted national laws addressing GD
-  Countries where cities have adopted specific laws addressing GD

-  Countries that have adopted a moratorium on the use of genetic test results by insurers
-  Countries that have taken a *status quo* approach
-  Countries that have adopted legally binding ethical guidelines