

# Revisiting Genetic Discrimination Issues in 2010: Policy Options for Canada



Policy Brief No. 2

## Editor's Preface

*GPS: Where Genomics, Public Policy and Society Meet* is an Ottawa GE<sup>3</sup>LS Series led by Genome Canada, in collaboration with several partners, to bring together federal policy-makers and leading researchers to explore options for addressing public policy issues at the interface of genomics and society. The resulting "Policy Directions Briefs" present the evidence base needed to support informed debate on a range of policy options, while deliberately stopping short of making any recommendations. Topics are selected on the basis of their broad societal importance, national interest, relevance to federal policy-makers, and "ripeness" for policy uptake.

Co-authors of the Policy Briefs are renowned leaders in the field commissioned by Genome Canada to synthesize the current state of academic knowledge on a given topic and translate it into a format and language familiar to senior federal policy makers. Co-authors are asked to present a well-balanced range of feasible policy options, as neutrally as possible, without favoring any particular position. The Policy Brief is not intended to reflect the authors' own views or opinions, nor those of Genome Canada.

The co-authors have benefited from valuable commentary of national and international experts and relevant stakeholders convened at a half-day event in Ottawa organized by Genome Canada and its Core Advisory Partners. In order to assure excellent quality, practical relevance and suitability for its intended purpose, the draft brief was then submitted to a small review committee in accordance with an explicit peer review process. The intent of these Policy Briefs is to provide a neutral, credible and legitimate source of information for policy-makers on important societal questions at the rock face of emerging genomic technologies and their applications.

- Patricia Kosseim

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## Executive Summary

Since the advent of the Human Genome Project, concerns have been raised about the potential inappropriate collection, storage and use of genetic information, particularly in the insurance and employment sectors. As genetic testing technologies become more readily available and affordable, their predictive capacity more accurate, marketing strategies more sophisticated, and access to online genetic information more pervasive, the incentives for third parties to mine and exploit this information will increase. The Council of Europe's *Convention on Human Rights and Biomedicine*, which explicitly prohibits genetic discrimination, prompted legislative initiatives in many countries. The U.S. has responded with state legislation and, federally, with the much-heralded but controversial *Genetic Information Non-Discrimination Act* (GINA) of 2008. GINA has created more recent pressure for a legislative response in Canada and has inspired the introduction of a federal private member's bill on genetic discrimination in 2010. Given recent developments, it may be time for Canada to revisit this policy issue. This Policy Brief explores three possible options (other than status quo) for addressing potential issues of genetic discrimination: 1) strengthened use of existing human rights and privacy regimes; 2) a new regulatory framework for genetic testing; and 3) sector-specific solutions for insurance.

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## I. The Context

Ever since the advent of the Human Genome Project, concerns have been raised about the potential inappropriate collection, storage and use of genetic information. Of particular worry has been genetic discrimination - the possible use of genetic information outside the context of health care and medical research to exclude individuals and their family members from a broad range of goods and services, including employment and insurance, but also education, adoption, and immigration, among others (Geller, 2002; Lemmens, Lacroix, Mykitiuk, 2007).

Numerous international (UNESCO, 2003; ECOSOC, 2004/9; HUGO, 2003) and national (ASHG, 2001; Lemmens, 2000) organizations have called for initiatives to prevent inappropriate genetic discrimination. The Council of Europe's Convention on Human Rights and Biomedicine (1997), which explicitly prohibits genetic discrimination<sup>1</sup>, is one of the most influential in this regard. Many member states have signed the Convention<sup>2</sup>, and legislative initiatives have been prominent<sup>3</sup>. In the US most states now have genetic discrimination statutes<sup>4</sup>, culminating in the much-heralded but controversial federal *Genetic Information Non-Discrimination Act* (GINA) of 2008.

In Canada, the Canadian Genome Analysis and Technology Program funded research and policy work in this area as early as 1992 (Knoppers, 1998), and a federal Inter-Departmental Initiative on Genetic Information and Privacy was undertaken in 2001-2002 (Dept. of Justice, 2003). Genetic discrimination has also received attention from other governmental agencies (OPC, 1992; OPC 2009-2010; OLRC, 1996; CHRC, 2001), advisory bodies and task forces (Provincial Advisory Committee on New Predictive Genetic Technologies, 2001; Conseil de la santé et du bien-être, 2001; Task Force on Insurance and Genetics, 2004; Knoppers and Joly, 2004) and academic commentators (Eltis, 2007; Lévesque and Avard, 2005; Knoppers and Joly, 2004; Florencio and Ramanathan, 2001; Lemmens, 1997, 2000). The adoption of GINA in the US has created more recent pressure in Canada for a legislative response<sup>5</sup>, and has inspired the introduction of a federal private member's bill on genetic discrimination (Bill C-508)<sup>6</sup>.

Given recent developments, it may be time for Canada to revisit the question of genetic discrimination. The amount of genetic information collected and stored in publicly funded biobanks is growing exponentially (Caulfield and Knoppers, 2009); patients increasingly have access to genetic testing in health care; and genetic testing companies now aggressively market directly to consumers over the internet. In the near future, people will be able to obtain a personal genome scan and more detailed genetic risk information. Other related forms of predictive testing are also gaining ground, such as epigenetic testing. As more tests become available more cheaply, as their predictive capacity increases, as marketing becomes more sophisticated, and as people have easier access to these technologies, there will be greater incentives for others to mine and exploit this information.

## II. The Issue

Genetic discrimination has received most attention in the employment and insurance sectors, in part as a result of the US debate where insurance and employment have been intrinsically linked. Given current applications and potential commercial incentives, Canadian concerns seem most pronounced in these sectors as well. Hence, this Policy Brief focuses on the employment and insurance sectors, though it is recognized that genetic discrimination may arise in other contexts as well.<sup>7</sup>

The employment and private insurance sectors present quite different contexts in which genetic information could be used, either positively or negatively. In the workplace, genetic tests could be used to identify workers' susceptibility to specific workplace toxins<sup>8</sup>, or their increased risk for a condition that could raise occupational health and safety concerns or seriously impair task performance<sup>9</sup>. Employers might also use genetic information to exclude those at higher risk of disease in order to avoid higher disability insurance costs, to reduce absenteeism and turnover, or to limit liability with regard to occupational health and safety.<sup>10</sup> While there is to date only limited evidence of genetic discrimination in employment<sup>11</sup>, a recent U.S. lawsuit suggests this is not just a rhetorical concern (Boston Herald, 2010).

Private insurance<sup>12</sup> is predicated on the ability to discriminate between clients on the basis of risk. Insurers collect information in order to rank applicants in actuarially-based risk groups, and charge premiums accordingly. Applicants are required by law to disclose information that is material to risk assessment, including medical and family histories (Lemmens, 2003). Insurers have generally been entitled to request genetic information in the broad sense (i.e., family history of disease), to access medical files, and to conduct medical tests. This information is used to determine premiums and to avoid adverse selection. Adverse selection occurs when insurance companies have higher than expected costs due to a disproportionate number of high-risk applicants or due to the fact that high risk applicants can apply for higher coverage without paying proportionally higher premiums. This can happen if applicants hide their risk status or if regulations prohibit insurers from charging a premium in line with higher risk status. As applicants gain easier access to commercial genetic testing, insurers may be more inclined to request genetic information from medical files or require applicants to undergo testing (Armstrong, 2003). One concern is that some individuals may forego medically-indicated genetic testing for fear that their insurability could be compromised if they have to disclose test results (Keogh et al, 2009).<sup>13</sup> Another concern is that individuals may be pushed to learn about risk factors they would prefer not to know, or for which they had not received adequate counseling (Laurie, 1999). On the other hand, genetic testing can also be beneficial for insurance applicants. For example, people with a family history of Huntington's who test negative for the gene

can show that they are not at risk and should be able to obtain standard insurance rates.

Although studies report cases of genetic discrimination in the context of insurance (Christiaans et al, 2010; Bombard et al, 2009; Barlow-Stewart et al, 2009; Hall et al, 2005; Otlowski, Taylor and Barlow-Stewart, 2002; Geller et al, 1996; Council for Responsible Genetics, 2001), it is often unclear whether the reported discrimination was perceived or actual, and/or whether discrimination occurred on the basis of a broad definition of genetic information (i.e., family history) or under a more narrow definition (i.e., DNA testing). There is presently no evidence of the widespread use of genetic testing by insurance companies. Given the rapid expansion of genetic testing, the exponential increase of genetic information available in health records and accessible indirectly through various on-line sources, such as health-information-sharing and other websites (Lemmens and Austin, 2009), it is timely to revisit the issue of genetic discrimination in Canada.

## III. Legal – Policy Background

Genetic discrimination can be 'rational' or 'irrational' depending on whether it is based on an accurate understanding of scientific findings (Rothstein and Anderlik, 2001). It can also arguably be fair or unfair depending on whether the use of genetic information is appropriate in specific contexts.

The term "genetic information" ranges from general information about family history, to medical information contained in health records, to specific results of DNA analysis (genetic testing). Genetic science and technology continue to evolve rapidly, and other related forms of testing (e.g., epigenetic testing)<sup>14</sup> can produce highly relevant information about a person's risk for disease. The discussion in this policy brief focuses on the results of DNA analysis (genetic testing), but may be relevant for other forms of testing as well.

The quality and predictive value of DNA analysis varies considerably. Most diseases are complex (e.g., arthritis, heart disease, most cancers) and involve interactions among numerous genes, environmental factors, life style choices and other variables, which limit significantly the predictive value of tests. Single gene disorders are rarer but the predictive value of single-gene tests can also vary considerably. For a highly penetrant single-gene disorder such as Huntington's, a test result is determinative. However, a positive test for a BRCA-gene associated with hereditary breast-cancer does not mean one will get cancer, nor does a negative test mean one will not develop the condition.

Currently in Canada, human rights and privacy law apply to some issues arising out of the use of genetic information, including genetic discrimination. The *Canadian Human Rights Act* and the human rights acts of all Canadian provinces explicitly prohibit dis-

crimination on specific grounds. Genetic information can be associated with several prohibited grounds, particularly disability.<sup>15</sup> The Canadian Supreme Court has defined disability widely as any condition or ailment -- real or perceived -- that is used to exclude someone (*Quebec v Boisbriand, 2000*).<sup>16</sup>

Even though genetic information can be considered a prohibited ground, under human rights law it can nonetheless be used to exclude someone from some goods or services if there is a 'Bona Fide Justification' (BFJ) or a "Bona Fide Occupational Requirement".<sup>17</sup> The *BFJ* test requires demonstration that a requirement is rationally connected to a legitimate goal, that it is enacted in good faith, reasonably necessary, and that no other accommodation is possible without undue hardship.<sup>18</sup> The *BFJ* test promotes substantive equality, a crucial component of Canadian law that imposes on both governments and private parties a duty to promote access to goods and services and to accommodate people. The *BFJ* test is context-specific and takes into consideration the nature of the good or service.

The scientific or evidentiary basis for a discriminatory standard is crucial in determining a *BFJ*. This requires solid evidence of the reliability of genetic tests and their overall predictive value (Lemmens and Thiery, 2007). The application of the *BFJ* test will be different in the insurance and employment contexts. In the insurance context, the insurers' goal of adjusting insurance premiums according to long-term risks and avoiding adverse selection is widely-considered as legitimate. While access to health information, including family history, may be rationally connected to this goal, what remains contested is whether, and to what extent, genetic test results are also reasonably necessary to achieve the goal. In the employment context, an employer's goals of promoting occupational health and safety of workers and reducing risks for the public, are similarly legitimate. However, the rational connection between these goals and the need to screen for and monitor long-term genetic risks may be more tenuous to establish. In both contexts, insurers like employers, must prove that there are no less discriminatory ways to achieve their goals and that they could not otherwise accommodate individuals without undue hardship. This means that they have to show that their business would be seriously undermined if they had to deal with this in a less discriminatory way.

Federal (PIPEDA, 2000)<sup>19</sup> and provincial<sup>20</sup> data protection statutes apply to personal information -- including health and genetic information -- and are based on internationally-recognized fair information principles (FIPs) such as, "consent", "limited use, collection and disclosure", "identification of purpose", "accuracy of data", "accountability" and "transparency".<sup>21</sup> Applying these principles to industry and employer practices is already complex and will be exacerbated by the advent of electronic health records and growing trend towards personalized medicine. For instance, the principle that an organization shall not, as a condition for supplying a product

or service, require an individual to consent to the collection, use, or disclosure of personal information beyond that required for an explicitly specified and legitimate purpose, may run counter to the principle of good faith contracts which requires full disclosure of all known information. The principle requiring organizations to collect personal information only for purposes which a reasonable person would consider appropriate in the circumstances may come up against insurers' or employers' desire to collect or use genetic test results which have not yet fully-established clinical utility. The principle of "individual consent" is particularly challenged by the inherently shared nature of genetic information common to families or entire communities.<sup>22</sup>

## IV. Policy Options

This Policy Brief canvasses three broad policy options for addressing potential genetic discrimination issues in Canada: 1) strengthening the use of existing Canadian human rights and/or privacy regimes; 2) introducing a new regulatory framework for governing genetic testing; and/or 3) initiating sector-specific solutions for insurance. Another option, not explicitly discussed, is maintenance of the status quo which affords no specific or differential treatment of genetic information.

### *Option 1 - Strengthen Existing Human Rights and Privacy Regimes*

Existing human rights and privacy regimes offer several avenues for addressing genetic discrimination. A human rights approach focuses on when the use of genetic information amounts to discrimination, while a privacy approach focuses on the circumstances under which collection, use and disclosure of genetic information are appropriate. Both approaches are corrective in that they offer rules and mechanisms in response to violations. But both can also play a pre-emptive, educative role through the development of guidelines or policies. Education is particularly important in the context of rapidly changing technologies as it can curtail premature and irrational use of such technologies, provide industry guidance and also reduce public anxiety.

Existing human rights regimes may be strengthened to address potential issues of genetic discrimination by: 1) developing interpretative, non-binding guidelines to clarify when genetic information constitutes a disability, or to specify which forms of testing or uses of information constitute a *BFJ*<sup>23</sup>; 2) issuing regulations that specify when accommodation creates undue hardship in the context of managing genetic risk; 3) amending the definition of 'disability' in human rights acts to expressly include 'the perception or belief that the person will have a disability in the future'<sup>24</sup>; or 4) introducing a new prohibited ground of discrimination that focuses specifically on genetic information (Bill C-508, 2010). Although this last option of explicitly capturing genetic information as a prohibited ground may

be criticized as promoting a form of “genetic exceptionalism”<sup>25</sup>, it also has the advantage of conveying expressive meaning and reflecting societal condemnation of inappropriate discrimination and stigmatization based on such traits (Hellman, 2003).

Existing privacy regimes could be enhanced to strengthen protection of genetic information by: 1) clarifying how the shared (familial) character of genetic information can be taken into account in privacy regimes which have traditionally focused on the individual; 2) identifying when the collection, use and disclosure of genetic information is appropriate in specific contexts, for which purposes and to what extent, including for example, restrictions on the type of information that can be transferred by physicians to employers and insurers<sup>26</sup>; or 3) investigating whether existing practices related to the collection, use and storage of genetic information create special privacy challenges and developing guidance documents to address these.

A key advantage of using existing regimes is that the potentially lengthy and cumbersome process of introducing major regulatory and legislative reform can be avoided. In addition, human rights and privacy agencies have well-established enforcement mechanisms and have developed considerable expertise in responding to related issues. Human rights law also has quasi-constitutional status, which offers additional protection. Disadvantages of these regimes include the fact that the rules are often general and may not be readily adaptable to rapid developments in genetics. Also, the dispute resolution process can be time consuming and costly. With respect to the policy and educational options, human rights and privacy commissions prioritize their work, and in the absence of systemic evidence that genetic discrimination is occurring, it may not always be viewed as an urgent concern.<sup>27</sup>

### ***Option 2 - Introduce a Comprehensive Framework to Govern Genetic Testing Technologies***

There is currently no comprehensive regulatory structure surrounding genetic testing technology (Provincial Advisory Committee, 2001; Ontario Report, 2002; CancerCare Ontario, 2008) and little provincial or federal government oversight (Adair et al, 2009)<sup>28</sup>. A mandatory approval process<sup>29</sup> and the establishment of a genetics advisory committee have been recommended in Canada (Ontario Report, 2002). A review process of genetic testing could be part of a comprehensive framework, established through stand-alone legislation.<sup>30</sup> A specialized genetic technology assessment committee could evaluate genetic testing and identify what tests could be conducted, by whom, and in what context (e.g., in employment or insurance). This committee could also determine whether test results already available in medical files could be used for non health-care related purposes. Review would focus on the quality, validity, value, and utility of proposed tests—which are also relevant to other debates surrounding genetic testing.<sup>31</sup> It could further determine the

need for genetic counseling and determine what information should be provided to those undergoing testing. The German Federal Parliament approved the establishment of such a review process involving a Genetic Diagnostic Commission.<sup>32</sup> An evaluation structure also exists in the U.K.<sup>33</sup> An advantage of a new regulatory framework is that it preemptively regulates what tests can be offered, by whom, and for what purpose, and how resulting information can be used (Lemmens, Lacroix and Mykitiuk, 2007). The process also stimulates the development of specialized knowledge around genetic testing which can inform other agencies (e.g., Human Rights or Privacy Commissions) (see Policy Option 1). The disadvantages of introducing a new regulatory regime include the significant costs and lengthy time involved with adoption.

### ***Option 3 - Initiate Solutions Specific to the Insurance Sector***

In several countries, distinctions are made between ‘luxurious’ and basic life insurance contracts.<sup>34</sup> For basic insurance up to a set amount, insurers cannot use genetic test results in setting premiums. For luxurious contracts, insurers can ask about prior tests and/or impose a genetic test.<sup>35</sup> This system guarantees access to some basic level of insurance, regardless of genetic risk status. It also reduces concerns about adverse selection by creating an equal playing field for all insurers. Some countries introduced this system through legislation, while in others it exists because of an agreement between the government and industry<sup>36</sup> (Lemmens and Bombard, forthcoming). Actuarial studies suggest that restricting the use of genetic information for insurance purposes does not necessarily have to lead to huge increases in insurance premiums. The impact is dependent on various factors, including the nature of the condition, the overall presence in the population, the type of insurance, and the availability of treatment options (Gui, Macdonald and Wekwete, 2006; Gutierrez and Macdonald, 2007; and Polborn, Hoy and Sadandand, 2006).

Changes to insurance law could alleviate some concerns related to the standard of disclosure and sanctions associated with non-disclosure. Some court decisions already reflect a desire to ameliorate the harsh consequences of non-disclosure through a flexible interpretation of disclosure obligations (Lemmens, 2004). Insurance statutes could be amended to accommodate such concerns, allowing the courts to consider explicitly the complexity of genetic information and the difficulty for insurance applicants to appreciate its relevance. In some countries sanctions for non-disclosure are proportionate to what was concealed or misrepresented by insurance applicants (McGleenan and Wiesing, 2000).

Industry organizations<sup>37</sup> and individual companies (Lohr, 2005) have already taken initiatives to self-regulate the use of genetic information. In some jurisdictions, the insurance industry has instituted a moratorium on the use of genetic testing (UK Concordat).<sup>38</sup> In

Canada, the insurance industry policy is that insurers will not require an insurance applicant to undergo genetic testing, but if genetic testing has been done and the information is available, the insurer will request access to that information.<sup>39</sup> Arguably, such moratoria exist because the availability and accuracy of genetic testing is still considered relatively limited (Lemmens, 2003, at 57). As more and better tests become available to consumers, industry incentives to access this information could make such moratoria tenuous.

Genetic testing standards and the policing of such could be implemented through self-regulation. The insurance industry has developed dispute resolution mechanisms, focusing on an insurance ombuds-service to field consumer complaints about insurance practices (e.g., OLHI). Should the industry introduce standards for the use of genetic information and genetic testing, or develop a system of basic versus luxurious contracts, such a self-regulated, dispute resolution system could be used by consumers.

## V. Application

The options canvassed above are not mutually exclusive and could work in concert to create a layered policy environment. Any policy option selected to address potential genetic discrimination issues, including status quo, should be based on available evidence and on a broad understanding of the social, cultural, and economic context in which related activities may occur.

Application of policy options will be influenced by one's views on the role of governments, markets, and professional associations in ensuring access to insurance and employment, on how one qualifies specific types of insurance (i.e., as private or public goods), and on the role of insurance in society. In the U.S., for example, health insurance has historically been viewed as a private good, and access to it has been largely linked to employment. As a result, exclusion from employment affects access to health care, and health insurance costs create incentives for employers to discriminate against people at increased risk for disease. This explains the very extensive genetic discrimination initiatives in the United States, including GINA which applies only to health insurance and employment. In Canada basic health insurance is viewed as a public good and access is not linked to employment, although private insurance plays an increasingly important role in providing access to health care, for example, to pharmaceutical products and 'additional' health services. Such considerations are relevant to any discussion of the role that legislative and policy initiatives might play in the Canadian context (Pullman and Lemmens, 2010).

## VI. Practical considerations

Several practical issues have to be considered when evaluating policy options in this area. Initiating major legislative reforms or amending existing legislative regimes can be time consuming and expensive. At the same time, the costs associated with some policy options (e.g., comprehensive review) may be counter-balanced by cost-savings in other regulatory areas (e.g., health care spending).<sup>40</sup> Any legislative reforms are further exacerbated by issues of federal-provincial jurisdiction (*Quebec v. Canada re: Assisted Human Reproduction Act*). Initiatives that single out genetic discrimination as somehow unique and worthy of free-standing legislation could face challenges from those who see other types of information as equally sensitive in nature, or from other vulnerable groups who might claim the need for greater protection. Also to be considered is whether it is fair to separate genetic from other types of health information, and the need to address definitional problems related to various policy or regulatory initiatives.

## VII. Future Research Questions

Several research questions merit further investigation. Additional empirical research, including anecdotal case studies, on the nature and extent of genetic discrimination in relation to new technological developments could be gathered. Evidence of discriminatory use of genetic information in Canada could be compared with that of other jurisdictions which already have genetics-specific policies in place. An assessment could be conducted of the potential actuarial and financial impact on the industry if it was prohibited from requiring individuals to undergo specific forms of susceptibility testing or requiring access to results of such testing as a condition of insurance.

## Endnotes

<sup>1</sup> Article 11 of the Convention prohibits discrimination on the grounds of genetic heritage; Article 12 restricts predictive genetic testing to health or scientific purposes.

<sup>2</sup> The Convention has been ratified by 26 countries and signed but not yet ratified by a further 8. For a list of the signatories and ratifications, see COE (1997).

<sup>3</sup> For comparative overviews of national initiatives, see for example, Gerards, Janssen and Heringa, 2005; King, Pillay and Lasprogata, 2006; Knoppers, Godard & Joly, 2004; Lemmens, 2003.

<sup>4</sup> Currently, 35 states prohibit genetic discrimination in hiring, firing, and/or terms, conditions or privileges of employment. In the health insurance context, 45 states do not allow the establishment of eligibility rules based on genetic information. See National Conference of State Legislatures, updated to January 2008.

<sup>5</sup> For example, the Canadian Coalition for Genetic Fairness is a coalition of organizations working to prevent genetic discrimination in Canada. See Jo Ann Watton (2008).

<sup>6</sup> The bill proposes to amend the *Canadian Human Rights Act* to add genetic information to its prohibited grounds of discrimination.

<sup>7</sup> For example, in workers' compensation investigations, genetic information may be used to deny claims based on pre-existing risk factors.

(Comment by Roxanne Mykitiuk at the Genome Canada GPS event (April 16, 2010).

<sup>8</sup> For example, alpha-1-antitrypsin deficiency, ataxia telangiectasia, and glucose-6-phosphate dehydrogenase deficiency. See Department of Health and Human Services (DHHS, 2009).

<sup>9</sup> For example hypertrophic cardiomyopathy could be considered a serious risk factor for a pilot, or a bus driver. See Kho and Jeyaratnam (1998).

<sup>10</sup> There have also been suggestions that genetic testing could be used to identify employment candidates' likelihood of having specific behavioral traits. Studies suggesting clear links between genetic mutations and behavioral traits have often been speculative and unconfirmed. Yet, one could imagine some employers using such tests prematurely to select employees for alleged behavioural traits.

<sup>11</sup> The most notorious example involves genetic testing for carpal tunnel syndrome undertaken by Burlington Northern and Santa Fe Railway Company. The company paid 2.2 million to settle a lawsuit with the U.S. Equal Employment Opportunity Commission (EEOC). See EEOC Press Release 05-08-02. For studies revealing discrimination in employment, see J.S. Alper et al., 1994; see also Library of Parliament (2010), which discusses the controversy surrounding an employment discrimination case in Germany. For documented historical instances of discrimination in employment, for example in the context of sickle cell screening, see Elaine Draper (1991).

<sup>12</sup> The term 'insurance' in this policy brief is generally used to refer to private commercial insurance contracts such as life insurance contracts, unless otherwise specified. We realize that different types of insurance contracts have different characteristics and that regulating the use of genetic information and genetic testing may face different challenges depending on the type of insurance contract. However, we cannot discuss here all different forms of insurance policies. The general policy options discussed here likely apply to various forms of insurance contracts based on individual risk assessment. But the implementation of these policy options would require careful assessment of how they impact on various forms of insurance.

<sup>13</sup> This concern was also expressed by genetic counselors participating in the Genome Canada GPS event (April 16, 2010).

<sup>14</sup> Epigenetics focuses on heritable changes to gene function that do not involve modifying the actual DNA sequence itself. A growing body of evidence shows that these changes affect gene-expression, and are highly relevant to determine disease risk levels. For a good discussion of the legal implications, see Rothstein, Cai and Marchant (2009). For a discussion of applications of epigenetics in the workplace, see DHHS (2009, at 13).

<sup>15</sup> While disability is the most obvious ground, the prohibited ground of ancestry (specified under some provincial human rights acts), could also be used (see OLRC, 1996 at 145-146). In addition, if genetic information is associated with a specific ethnic or racial group, it may also be qualified as discrimination on ethnic or racial grounds. Categorizing genetic discrimination in this way may offer additional protection, since the exceptions to the discrimination prohibitions never apply in cases of discrimination based on race or ethnicity. See the general discussion in Lemmens, Lacroix, and Mykitiuk (2007).

<sup>16</sup> This decision involved three cases of employment discrimination, where employees were excluded on the basis of asymptomatic conditions. In obiter, the Court explicitly referred to genetic testing when defining a broad concept of disability.

<sup>17</sup> For brevity purposes, we will use only the general term BFJ and include in that term justifications in the provision of goods and services as well as in the employment context. In the employment contexts, the specific terms Bona Fide Occupational Requirement (BFOR) or Bona Fide Occupational Qualification (BFOQ) are used. In the Canadian context, a uniform test has been introduced to determine when a discriminatory distinction can be justified, which supports in our opinion the use of one general term.

<sup>18</sup> The Supreme Court embraced this uniform BFJ test in *British Columbia v. Meiorin* (1999); and developed it also further in *British Columbia v. Grismer* (1999). Since *Meiorin*, no distinction is made in Canadian law between direct and indirect discrimination.

<sup>19</sup> PIPEDA does not apply uniformly across the country, as individual provinces can apply their own legislation if it is deemed substantially similar to PIPEDA. Some provinces have specific health privacy legislation in addition to other privacy legislation. Which statute applies will depend on the province, the type of business (public, private or federally regulated), the type of transaction (commercial or not), the kind of information (health or personal), or even the person who handles it. Quebec, British Columbia, Alberta and Ontario have provincial privacy legislation deemed 'substantially similar' to PIPEDA. (Note that Ontario is only partially 'substantially similar' since the act focuses on health information).

<sup>20</sup> For example, Ontario has enacted PHIPA (2004). This statute follows PIPEDA principles, but contains more detailed and specific guidance on how personal health information should be handled.

<sup>21</sup> Genetic information is not explicitly included in Canadian privacy statutes, but it is generally accepted that genetic information falls under personal information or personal health information (see e.g., OPC, 1992; O'Capella, 2004, at 12-13; Bahamin, 1995; and Levesque, Avard and Knoppers, 2005-06).

<sup>22</sup> People may thus have a privacy interest in the genetic information of family members. See for example Gudmundsdottir v. Iceland (2003).

<sup>23</sup> Various human rights commissions have developed guidelines and policies related to BFJ and undue hardship. Some policies specify, for example, how medical testing can be conducted in the workplace. These policies already provide guidance on how occupational health-focused genetic testing could be conducted (e.g., only after an initial offer of employment is made). See for example OHRC (2000, with minor revisions December 2009) and Manitoba HRC (2002). Human rights commissions have also published extensive reports on how the duty to accommodate can best be accomplished (see e.g., CHRC, 2006).

<sup>24</sup> See OLRC (1996) and CHRA Review Panel (2001, Recommendation 119). This more clearly includes future disability or illness associated with genetic mutations in an existing prohibited ground of discrimination, while avoiding criticism that genetics is singled out for special protection. Protecting one ground of discrimination without similar protection for comparable traits can also trigger human rights concerns. See for example *Battlefords and District v. Gibbs* [1996].

<sup>25</sup> Genetic exceptionalism is a term used to qualify policy and legislative initiatives that single out genetics as a special category. Critics of these initiatives argue that genetic information is not different from other types of health information and that these approaches amount to genetic exceptionalism, which may further stigmatize those with genetic conditions or those who have a genetic susceptibility or increased risk for disease.

<sup>26</sup> Some international data codes of practice specify that genetic test results cannot be disclosed to insurers and must be deleted from the files if they are disclosed (see e.g., Ireland, 2008).

<sup>27</sup> It should be noted that the Office of the Privacy Commissioner of Canada has recently identified Genetic Information and Privacy as one of its four strategic priorities. See OPC (2010-2011).

<sup>28</sup> Only *in vitro* diagnostic laboratory genetic test kits are subject to review under the *Food and Drugs Act* as “medical devices” (Ries, 2008). These kits undergo regular quality assurance review, but this falls short of a comprehensive regulatory review and approval process. In addition, genetic tests created by labs in-house from component parts (i.e., not purchased as “kits”) are not covered. See also Hogarth, Javitt, and Melzer (2008).

<sup>29</sup> This is recommended in, for example, CancerCare Ontario (2008).

<sup>30</sup> A key question will be whether this is to be realized through federal or provincial legislation, or through interprovincial-federal collaboration. *The Assisted Human Reproduction Act* is an example of a comprehensive federal regulatory initiative in a broad area of new medical technology.

<sup>31</sup> For example in the context of concerns raised by direct-to-consumer genetic testing, which will be the issue addressed in Genome Canada GPS Event no. 3 (June 29, 2010).

<sup>32</sup> *Human Genetic Examination Act* (2009). The statute also contains rules about genetic discrimination, genetic counseling, and specific rules about employment and insurance testing.

<sup>33</sup> This evaluation structure is not based on a statute. The Human Genetics Commission, an advisory body to the government, provides independent evaluation of genetic testing. It appears to have significant impact also on industry practice. Its predecessor evaluated, for example, the genetic test for Huntington's, and concluded that it could be used for insurance purposes (Genetics and Insurance Committee, Press Release, 2000).

<sup>34</sup> In some countries, this has been done through legislation. See for example, the Netherlands (1997) and Germany (2009). In the U.K., this system has been implemented through a ‘concordat,’ or high level policy agreement between the Government and the Insurance Industry (UK Concordat).

<sup>35</sup> Under the draft German legislation, insurers would not be allowed to request a genetic test, but they could request access to test results for insurance contracts above Euro 300,000 (or annuities of Euro 30,000).

<sup>36</sup> See for example legislation in the Netherlands (1997) and Germany (2009). In the U.K., this system has been implemented through a ‘concordat,’ or high level policy agreement between the Government and the Insurance Industry (UK Concordat).

<sup>37</sup> The insurance industry has, for example, actively promoted privacy standards related to health information.

<sup>38</sup> It should be noted that this moratorium was issued under pressure from government.

<sup>39</sup> In 2000, the Canadian Life and Health Insurance Association (CLHIA) issued a position statement on the use of genetic information which was updated in 2003 and in 2010, see CLHIA (2010); see also the discussion in Lemmens, Joly, Knoppers (2004).

<sup>40</sup> A recent study examined public attitudes in Canada regarding willingness to pay for genetic testing, including willingness to pay out of pocket, and expectations of coverage from the public health insurance system for different types of tests (Ries, Hyde-Lay and Caulfield, 2009).

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