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A BRAVE NEW **W**ORLD:

Where Biotechnology
and Human Rights Intersect

Chapter 5

Human Rights Issues Related to
Genetic Information and Privacy

A Brave New World: Where Biotechnology and
Human Rights Intersect

July 2005

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Human Rights Issues Related to Genetic Information and Privacy

Matthew Taylor

5.1 Introduction

The rapid and ongoing scientific advancement in the area of genetic information brings with it a complex set of legal, social and policy issues. Genetic information is a broadly understood concept that encompasses various elements, including information obtained through genetic research, as well as information related to family health history.¹ Genetic information can be ascertained through a variety of sources and can serve many useful purposes, some of which include:

- determining paternity;
- assisting in making reproductive choices and decisions relating to reproduction generally; and
- assisting in predicting, diagnosing, treating and preventing health conditions.²

Most importantly, genetic information about an individual is personal information.³ It can, moreover, encompass aspects of information that tend to be highly sensitive in nature. This chapter will highlight some of the major legal and human rights issues that relate to genetic information. In particular, this chapter will canvass two significant areas: discrimination and privacy.

Within the context of discrimination, specific attention will be paid to the areas of employment and insurance. The discussion of privacy will focus on whether or not an individual has the right to know or not know their genetic information or that of a close family member. Further,

issues relating to confidentiality of results of genetic testing will be examined.

In discussing these issues, this chapter will, for the most part, summarize the work done by the Genetic Information and Privacy Inter-departmental Working Group (“WG”).

The WG was created in the fall of 2001 and has identified many challenges associated with genetic information. The WG has developed a national strategy designed to enhance privacy protection and freedom from discrimination on the basis of genetic information. The strategy is also geared towards providing individuals the ability to benefit from genetic research and health innovation. One way the WG is implementing this strategy is by looking at the existing legislative and policy frameworks dealing with privacy and discrimination with a view to strengthening these mechanisms in a way that deals with the issues posed by genetic information.

The issues of privacy and discrimination on the basis of genetic information will be analyzed within the domestic and international frameworks, including the approach of other jurisdictions. Where possible, gaps in the Canadian framework will be identified.

¹ See T. Lemmens and L. Austin, “Of Volume, Depth and Speed: The Challenges of Genetic Information” (February 2001) [unpublished], prepared for the Canadian Biotechnology Advisory Committee.

² E. O’Scapella, “Genetics, Privacy and Discrimination: A Survey Prepared for the Canadian Biotechnology Advisory Committee” (31 October 2000) [unpublished] at 8.

³ E. O’Scapella, “Genetic Testing in Employment: A Review of Legislation and Policy Issues” (3 January 2003) [unpublished] at 11.

5.2 The Science

The nuclei of all human cells, except sperm and egg cells, contain 23 pairs of chromosomes (46 in total – 23 from each parent), which are composed of deoxyribonucleic acid (“DNA”).⁴ Essentially, DNA is the carrier of the genetic instructions for making living organisms.⁵ Each human cell contains thousands of genes, which are short sections of DNA, that act either together or independently to produce proteins.⁶ These proteins are essential for the following processes: providing cell structures, producing hormones, and transporting substances throughout the body.⁷ When proteins are not synthesized properly, it may be assumed that the genetic information that instructs its creation is at fault.⁸ Thus, understanding the genetic anomaly behind the improperly created protein is an important step in understanding how to devise treatments for those persons with genetic conditions.

An individual may have a genetic mutation that results in a particular disease or disorder. The most commonly tested for single gene disorders are cystic fibrosis, beta-thalassaemia and Huntington’s disease. As scientific knowledge regarding the human genome increases, the number of diseases, such as heart disease and certain cancers, for which a predisposition can be determined through genetic testing, will also increase.⁹

It is important to note that, at this point in time, genetic tests only reveal whether an individual is likely to develop a genetic disease or disorder but not the degree to which the condition will affect the individual.¹⁰

5.3 Obtaining Genetic Information: Methods of Genetic Testing

Genetic information can be obtained through different means and for different purposes. Information can be obtained through DNA testing, indirect genetic testing and through family medical history.¹¹ In addition to the various methods that can be utilized to obtain genetic information, genetic testing can be employed at different stages in one’s lifetime. For instance, testing can be done pre-conception on sperm or ova; *in vitro*, on an embryo created outside the body; and pre-natal, on the foetus. It can also be done at the time of birth in an effort to reduce the progression of

diseases that require early detection and treatment. Finally, genetic testing can be done at any other point in time to assess the likelihood of potential genetic disorders.¹²

5.3.1 DNA Testing

Through the analysis of DNA, scientists have been able to assess whether individuals contain genetic mutations known to be indicators of various diseases, such as Alzheimer’s disease, cystic fibrosis, sickle cell anaemia and Tay-Sachs disease.¹³ DNA testing provides scientists the information that enables them to physically map different genes, showing their size, order and numbering.¹⁴ DNA testing is becoming more common, and is, perhaps, one of the more sophisticated ways of obtaining genetic information. DNA testing has improved greatly over the past few decades as a result of incredible advances in scientific technology.

5.3.2 Indirect Genetic Testing

Another method employed to obtain genetic information is through indirect genetic testing. One type of indirect genetic testing is through analyzing bodily substances such as urine, blood or other bodily fluids. It can also be accomplished through the identification of visible characteristics caused by genetic conditions.¹⁵ For example a diagnosis of spina bifida, a birth defect where the spine does not form completely, is a

⁴ S.A. Sherwood, “Don’t Hate Me Because I’m Beautiful... and Intelligent... and Athletic: Constitutional Issues in Genetic Enhancement and the Appropriate Legal Analysis” (Summer, 2001) 11 Health-Matrix: Journal of Law-Medicine 633 at 635.

⁵ Ontario: Ministry of Health, “Genetic, Testing and Gene Patenting: Charting New Territory in Health Care” online: http://www.health.gov.on.ca/english/public/pub/ministry_reports/geneticsrep02/report_e.pdf accessed: 09 January 2004 11:20AM.

⁶ S.A. Sherwood, *supra* note 4 at 635.

⁷ Online: <http://www.ontariogenomics.ca/gc/ogi/aboutGenomics/whatsGenomicsOGI.asp?l=e> accessed 08 January 2004 9:37AM.

⁸ *Ibid.*

⁹ Kay Chung, *Designer Myths: the Science, Law and Ethics of Preimplantation Genetic Diagnosis* (London: Progress Educational Trust, 1999) at 10-11.

¹⁰ Maha F. Munayyer, Genetic Testing and Germ-Line Manipulation: Constructing a New Language for International Human Rights (1997) 12 Am. U.J. Int’l L. & Pol’y 687 at 3 (Lexis Nexis).

¹¹ T. Lemmens and L. Austin, *supra* note 1 at 6-7.

¹² *Ibid.* at 8-9.

¹³ *Ibid.* at 6-7.

¹⁴ *Ibid.* at 6.

¹⁵ *Ibid.* at 7.

form of indirect genetic testing because the visible characteristics associated with this illness are known to be caused by genetic anomalies. A further method of obtaining genetic information through indirect testing involves chromosomal analysis where abnormalities can be seen. One example of chromosomal analysis is amniocentesis.¹⁶

5.3.3 Family History

One of the more traditional ways to ascertain genetic information about an individual is through the taking of a detailed family medical history. It is well known that certain diseases are hereditary and that individuals within some families are more susceptible to a particular disease given that close family members have the disease and that the family shares certain genetic characteristics. Examples of conditions that have a genetic basis include breast cancer and Huntington's disease.¹⁷ A family medical history is one source of genetic information that can lead to the identification of "at risk families".¹⁸

5.4 Comparative Legal Approaches to Genetic Information

The legal protection granted to genetic information varies from jurisdiction to jurisdiction. This variance is partially a result of the different ways countries have conceptualized genetic information. For instance, in Australia genetic information is encompassed by the larger concept of health information.¹⁹ This is also the case in Iceland, although in Iceland health information is further subsumed in the broader concept of personal data.²⁰ In the United Kingdom ("U.K."), genetic information is considered "sensitive personal data".²¹ Finally, in India there is no general data-protection legislation, however the government protects privacy rights during the course of biomedical research through measures provided by the Department of Biotechnology.²²

5.5 Canadian Context

Genetic information is afforded protection through legislation and the common law in Canada. Canada's protection of genetic information varies depending on which level of government or jurisdiction is engaged, as well as the particular legislation involved. "Genetic

information" is not specifically defined in many of the pieces of legislation that nonetheless may protect the rights of individuals from invasion of privacy and discrimination on the basis of genetic information. In other pieces of legislation, genetic information is defined.

Protection of personal information occurs through a variety of mechanisms under the legal frameworks dealing with either privacy or discrimination. Under the privacy framework, genetic information is afforded some legal protection by the *Canadian Charter of Rights and Freedoms*²³ (the "Charter"), the federal *Privacy Act*,²⁴ the federal *Personal Information Protection and Electronic Documents Act*²⁵ ("PIPEDA") and provincial²⁶ privacy and freedom of information legislation.

The *Charter* protects against state incursions into a person's reasonable expectation of privacy. The *Charter's* application encompasses all actions and laws of the government, although it does not generally apply to actions of private actors.

Neither the *Privacy Act* nor *PIPEDA* specifically identifies "genetic information". Rather, they apply to "personal information" which arguably would include genetic information. Some of the provincial statutes are more explicit in extending protection to genetic information by including "inheritable characteristics" or "genetic information" in the definition of personal information.²⁷

¹⁶ *Ibid.*

¹⁷ *Ibid.* at 8.

¹⁸ *Ibid.*

¹⁹ M. Letendre, C. Sallée et al., "Genetic Privacy: A Comparative Approach" (14 March 2003) [unpublished] at 9.

²⁰ *Ibid.* at 15.

²¹ *Ibid.* at 12.

²² *Ibid.* at 16-17.

²³ Enacted as Schedule B to the *Canada Act 1982* (U.K.) 1982, c. 11 which came into force 17 April 1982.

²⁴ R.S.C. 1985, c. P-21.

²⁵ S.C. 2000, c.5.

²⁶ In this paper, the words "province" and "provincial" include the Canadian territories.

²⁷ See Alberta's *Freedom of Information and Protection of Privacy Act*, R.S.A. 2000, c. F-25; Manitoba's *Freedom of Information and Protection of Privacy Act*, C.C.S.M. c. F175; Nova Scotia's *Freedom of Information and Protection of Privacy Act*, S.N.S. 1993, c. 5; Yukon's *Access to Information and Protection of Privacy Act*, R.S.Y. 2002, c. 1; and Northwest Territories' *Access to Information and Protection of Privacy Act*, S.N.W.T. 1994, c. 20.

Under the discrimination framework, protection can be found in Canadian human rights legislation. For instance, the federal *Canadian Human Rights Act*²⁸ and the corresponding provincial human rights statutes prevent discrimination against individuals in the area of employment and the provision of various services. The discussion that follows will explore whether or not individuals may be protected from discrimination on the basis of genetic information under the current legal framework in Canada.

5.6 Issue 1: Discrimination

As discussed above, advances in genetic research allow scientists to identify susceptibilities that individuals may have to a variety of diseases thus providing an opportunity to predict an individual's predisposition to certain conditions. These scientific developments provide the possibility for treatment to either decrease the severity of or to prevent possible disorders from manifesting, thereby providing hope to individuals and families who are genetically predisposed to disease.

However, obtaining information in advance with respect to an individual's risk of developing a genetic disorder could lead to discrimination in a variety of ways. For instance, insurance providers may refuse to insure persons who are predisposed to a particular disease. Similarly, predisposed individuals may find it difficult to obtain a job. In industries where employers often arrange for private health benefits for their employees there may be reluctance amongst employers to hire or retain employees who are genetically at risk of developing a debilitating illness which would prevent them from returning to work. Employers may simply refuse to hire these individuals on the basis of this risk and potential costs to their health plan. Even if employment is found, employers may assign individuals to certain positions based on perceived health risks or, alternatively, limit that individual's opportunities within the workplace. Other areas where there is a risk that genetic information can be used to discriminate include allocation of health resources, immigration screening and custody determination in family law matters.

This section will begin with a brief overview of the international and comparative frameworks relating to the area of genetic information and discrimination. It will then review

the principles informing the Canadian legal approach to discrimination. Finally, it will turn to an analysis of issues that arise in the case of discrimination based on genetic information within the employment and insurance contexts.

5.6.1 The International Context

With respect to international law, there are few references to genetic information and discrimination. However, work has recently been undertaken to address the impact of advances in genetics. For instance, the 1997 UNESCO *Declaration on the Human Genome and Human Rights* encourages countries to prohibit discrimination based on genetic information.²⁹ The *Declaration*, which was adopted on 11 November 1997, recognizes the right of everyone to respect for their dignity and human rights regardless of their genetic characteristics.³⁰ The following year, it was endorsed by the United Nations General Assembly.³¹ Similar efforts have been made in Europe with the 1997 *Convention on Human Rights and Biomedicine*,³² which prohibits all forms of discrimination based upon genetic information. Canada is not a party to the European Convention and is therefore not bound by it. Finally, on 16 October 2003 the UNESCO *International Declaration on Human Genetic Data* was adopted unanimously at the 32nd session of the General Conference.³³ The *Declaration* aims to "ensure the respect of human dignity and protection of human rights in the collection, processing, use and storage of human genetic data."³⁴

5.6.2 The Comparative Context

Several countries have dealt with the issue of discrimination on the basis of genetic information. For example, France has had legislation for some time prohibiting discrimination on the basis of genetic characteristics.³⁵

²⁸ R.S.C. 1985, c. H-6.

²⁹ *Universal Declaration on the Human Genome and Human Rights*, 11 November 1997, UNESCO, 29th Sess., (adopted unanimously and by acclamation). Under international law, a Declaration is not binding on state parties but rather a sign of support for the principles contained therein. For more information see chapter 1 *supra*.

³⁰ E. O'Connell, *supra* note 2 at 19.

³¹ GA Res. A/RES/53/152, UNGAOR, 53d Sess., (1998).

³² ETS No. 164.

³³ *International Declaration on Human Genetic Data*, 16 October 2003, UNESCO, 32nd Sess., (adopted unanimously and by acclamation).

³⁴ *Ibid.*

³⁵ See article 16-13 of the *Civil Code*, Book 1/Title1/Chapter 2.

In the United States (“U.S.”), a number of states have enacted legislation dealing with the use of genetic information in the workplace and, in 2000, an executive order was signed by President Bill Clinton preventing every federal department from using genetic information in any hiring or promotion action.³⁶ Further, on 14 October 2003, the U.S. Senate passed Bill S 1053 prohibiting discrimination on the basis of genetic information in the areas of employment and health insurance.³⁷

In Australia, the Law Reform Commission is proposing to add discrimination on the grounds of genetic status to its anti-discrimination legislation. Genetic information is also being addressed through a variety of legislative regimes in other countries including Iceland, the U.K. and India.

5.6.3 The Canadian Context

Understanding Discrimination

The Supreme Court of Canada’s (“SCC”) 1999 decision in *Law v. Canada*³⁸ discussed the difficulty which exists in trying to define the concept of “discrimination” given its abstract nature.³⁹ What is clear, however, is the importance of focussing on the realization of human dignity, the disregard of which leads to discrimination. In this regard, the Court noted:

It may be said that the purpose of s. 15(1) is to prevent the violation of essential human dignity and freedom through the imposition of disadvantage, stereotyping, or political or social prejudice, and to promote a society in which all persons enjoy equal recognition at law as human beings or as members of Canadian society, equally capable and equally deserving of concern, respect and consideration. Legislation which effects differential treatment between individuals or groups will violate this fundamental purpose where those who are subject to differential treatment fall within one or more enumerated or analogous grounds, and where the differential treatment reflects the stereotypical application of presumed group or personal characteristics, or otherwise has the effect of perpetuating or promoting the view that the individual is less capable, or less worthy of recognition or value as a human being or as a member of Canadian society.⁴⁰

In essence, discrimination results when individuals or groups are unfairly disadvantaged by a government measure, based on their personal characteristics, in a manner that offends their human dignity. In Canada, complaints about discriminatory conduct can be addressed through different mechanisms. The *Charter*, as well as federal and provincial human rights legislation, provides individuals protection from discriminatory conduct.

The Charter

Section 15 of the *Charter*, the equality provision, provides every individual protection from discrimination. It reads:

15 (1) Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.

(2) Subsection (1) does not preclude any law, program or activity that has as its object the amelioration of conditions of disadvantaged individuals or groups including those that are disadvantaged because of race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.

The grounds set out in s. 15 of the *Charter* are not meant to be exhaustive. Rather, protection from discrimination based on personal characteristics includes both the enumerated grounds listed within the section, and analogous grounds.⁴¹

An individual’s predisposition to a particular disease, evidenced through the analysis of their genetic information, could potentially be included under mental or

³⁶ E. Oscapella, *supra* note 2 at 13.

³⁷ Online: <http://thomas.loc.gov> (accessed 14 January 2004).

³⁸ [1999] 1 S.C.R. 497 (hereinafter “*Law*”).

³⁹ *Ibid.* at para. 52.

⁴⁰ *Ibid.* at para. 51.

⁴¹ The Supreme Court of Canada in *Corbiere v. Canada*, [1999] 2 S.C.R. 203 at para. 13 defined analogous grounds as those “characteristics that we cannot change or that the government has no legitimate interest in expecting us to change to receive equal treatment under the law.” The Court has recognized a variety of analogous grounds including sexual orientation (See *Egan v. Canada*, [1995] 2 S.C.R. 513) and citizenship (See *Andrews v. Law Society of Upper Canada*, [1989] 1 S.C.R. 143).

physical disability and thus be afforded protection under s. 15 of the *Charter*. The SCC has had various opportunities to consider the notion of disability. The crux of these decisions recognizes that disability is not simply defined by reference to a biomedical condition, but also includes the societal response to those conditions.⁴² The Court noted the following on disability in *Québec (Commission des droits de la personne et des droits de la jeunesse) v. Boisbriand (City)*:⁴³

... a “handicap” may be the result of a physical limitation, an ailment, a social construct, a perceived limitation or a combination of all these factors. Indeed, it is the combined effect of all these circumstances that determines whether the individual has a “handicap”...

It is important to note that a “handicap” may exist even without proof of physical limitations or the presence of an ailment. The “handicap” may be actual or perceived and, because the emphasis is on the effects of the distinction, exclusion or preference rather than on the precise nature of the handicap, the cause and origin of the handicap are immaterial.⁴⁴

Similarly, in *Granovsky v. Canada*,⁴⁵ the Court noted:

The true focus of the s. 15(1) disability analysis is not on the impairment as such, nor even any associated functional limitations, but is on the problematic response of the state to either or both of these circumstances. It is the state action that stigmatizes the impairment, or which attributes false or exaggerated importance to the functional limitations (if any), or which fails to take into account the “large remedial component” [citation omitted] or “ameliorative purposes” [citation omitted] that creates the *legally relevant* human rights dimension to what might otherwise be a straightforward biomedical condition.⁴⁶ [emphasis in original]

The current jurisprudential approach to disability under s. 15 of the *Charter* may provide a legal mechanism to protect individuals from government discrimination on the basis of perceived disability due to genetic predisposition.

Human Rights Legislation

The *Canadian Human Rights Act*⁴⁷ protects individuals from discrimination in matters that come within the purview of the legislative authority of Parliament, such as banks and airlines.⁴⁸ The Act prohibits discrimination on the basis of disability, which is the most likely ground that would include and protect individuals whose genetic information indicates they are at risk of disease. The 2000 “La Forest Report,” a major review of the *Canadian Human Rights Act*, recommended that the definition of disability under that Act be amended to include the predisposition to being disabled.⁴⁹ At present, the Act does not explicitly define disability to include predisposition to disability.

At the provincial level, legislation exists to protect individuals from discrimination based on disability (or handicap) within their respective spheres of competence. For instance, the *Ontario Human Rights Code*⁵⁰ prohibits discrimination in the areas of employment, accommodation and the provision of services.

Legislation in Ontario and Nova Scotia makes it clear that protection extends to cases of perceived disability. In Ontario, “because of handicap” means for the reason that the person is believed to have or have had any degree of physical disability, birth defect or illness. In Nova Scotia, physical disability or mental disability is defined to include perceived physical and mental disabilities.

Alberta, Saskatchewan, and Newfoundland define disability to include any degree of disability caused by a birth defect. This could lend itself to include a predisposition to a disability caused by a birth defect. Prince Edward Island defines a physical or mental handicap

⁴² N.M. Ries, “Discrimination, Disability and Privacy: Judicial Interpretations and Implications Regarding Use of Genetic Information” (March 2003) [unpublished] at 14.

⁴³ [2000] 1 S.C.R. 665 (hereinafter “*Boisbriand (City)*”).

⁴⁴ *Ibid.* at para. 76.

⁴⁵ [2000] 1 S.C.R. 703 (hereinafter “*Granovsky*”).

⁴⁶ *Ibid.* at para. 26.

⁴⁷ *Supra* note 28.

⁴⁸ *Ibid.* s. 2.

⁴⁹ Canada, Minister of Justice and the Attorney General of Canada, *Report of the Canadian Human Rights Act Review Panel* (Ottawa: Canadian Human Rights Act Review Panel, 2000) (Chair: The Honourable Gérard V. La Forest) (hereinafter “La Forest Report”).

⁵⁰ R.S.O. 1990, c. H.19.

as a previous or existing disability caused by a birth defect. This definition could lead to a limited interpretation that includes a predisposition to disability. British Columbia and Manitoba have no definition of disability.

A majority of the provinces exempt providers of insurance that base an exclusion on reasonable or bona fide grounds because of disability.⁵¹ As with federal legislation, the corresponding provincial human rights statutes prohibit discrimination on the basis of “disability” or “handicap”. And like their federal counterpart, it is likely that this prohibition would encompass predispositions to disease or illness determined through the analysis of genetic information. It appears, however, that to date none of the provincial or territorial statutes explicitly define disability to include a predisposition to disease.

5.6.4 Issues Arising in the Employment Context

All human rights legislation in Canada prohibits discrimination in employment based on disability or handicap.⁵² Additionally, the *Charter* regulates the conduct of the federal and provincial governments qua employer. If a genetic predisposition to disease falls within the purview of disability, individuals would have grounds under human rights legislation and the *Charter* to challenge discrimination. Having said this, under human rights legislation, an employer may refuse to hire an individual if they are able to establish a bona fide occupational requirement. If the employer can prove that a bona fide occupational requirement exists, then no discrimination is found under the legislation. The test for finding a bona fide occupational requirement has been articulated in two SCC decisions.⁵³

Issues of discrimination on the basis of genetic information could potentially arise at various stages within the employment context. Genetic screening is a one-time testing of workers to determine individual susceptibility to existing workplace hazards or suitability to perform job functions.⁵⁴ An employer may be interested in utilizing genetic screening pre-employment, at the time of hiring, and post-hiring.⁵⁵ The use of such screening could lead to issues of discrimination in the workplace.

Offers or terms of employment tied to the genetic disposition of a particular individual may give rise to allegations of discrimination. However, the employer may be able to

justify these requirements. If a potential or current employer seeks to limit opportunities within a workplace on the basis of genetic information obtained through genetic screening, the onus will be on the potential or current employer, once a *prima facie* case of discrimination has been made out, to show that such measures are bona fide occupational requirements.

Clearly, the possibility exists for genetic information-based employment discrimination. Some have suggested that employment discrimination based upon a predisposition or perceived predisposition would be prohibited under human rights legislation.⁵⁶ As noted above, the 2000 La Forest Report recommends amending the definition of disability under the *Canadian Human Rights Act* to clearly include predisposition to illness.⁵⁷ This recommendation would apply to matters falling within the sphere of federal jurisdiction. Provincial human rights legislation would not be affected by the implementation of such a recommendation. At present there remains no explicit prohibition against discrimination on the basis of predisposition to illness under federal or provincial legislation.

5.6.5 Issues Arising in the Insurance Context

Insurance is a contract between an insurer and an insured in which the insurer agrees to underwrite a risk in return for a payment from the insured.⁵⁸ Insurance companies

⁵¹ Including British Columbia, New Brunswick, Newfoundland, Nova Scotia, Ontario, Saskatchewan, Prince Edward Island, Quebec and Yukon.

⁵² N.M. Ries, *supra* note 42, at 18.

⁵³ *British Columbia (Public Service Employee Relations Commission) v. British Columbia Government and Service Employees' Union (B.C.G.S.E.U.)*, [1999] 3 S.C.R. 3 (hereinafter “*Meiorin*”), and *British Columbia (Superintendent of Motor Vehicles) v. British Columbia (Council of Human Rights)*, [1999] 3 S.C.R. 868 (hereinafter “*Grismer*”). In *Grismer*, the Court articulated the test for finding a bona fide occupational requirement at para. 20 as follows:

- (1) Is the discriminatory standard rationally connected to the function being performed?;
- (2) Did the defendant adopt the particular standard with an honest and good faith belief that it was necessary for the fulfillment of its purpose or goal?; and
- (3) Is the standard reasonably necessary for the defendant to accomplish its purpose or goal?

⁵⁴ THiNC Health Inc., “Genetic Information: Domestic Health, Insurance, and Employment Sector Issues for the Federal Government. A Report for the Federal Working Group on Genetic Privacy and Information” (March 2001) [unpublished] at 52-53.

⁵⁵ *Ibid.* at 53.

⁵⁶ See E. Oscanella, *supra* note 3 at 26-27; N.M. Ries, *supra* note 42 at 15.

⁵⁷ *Supra* note 49 at recommendation 119.

⁵⁸ THiNC Health Inc., *supra* note 54 at 43.

assign a level of risk to individuals which determines whether an individual will be insured, and if so, at what cost. Insurance companies may exhibit greater reluctance to insure individuals who suffer from or are at a high risk of illness. Consequently, access to genetic information that discloses a predisposition to illness can play a significant role in the ability of these individuals to obtain insurance.

Genetic information has the potential to separate those who have access to insurance because of their genetic makeup from those who do not.⁵⁹ It might also result in those who are predisposed to genetic conditions being required to pay higher premiums due to the increased risk associated with insuring them. Human rights legislation does not prevent discrimination in the insurance context.⁶⁰ Accordingly, there exists a real possibility that the use of genetic information in this context will have a significant impact on the ability of individuals who are genetically predisposed to illness to obtain insurance.⁶¹ Moreover, requiring genetic information to be disclosed to insurance companies may also have a chilling effect on advance diagnoses of medical conditions. Individuals may be disinclined to seek out genetic information about themselves if they would be required to disclose the information to insurance providers.

There are two questions that arise: (1) whether the insurance industry will require genetic information when assessing applications for insurance, and (2) whether individuals will be denied insurance on the basis of their genetic information. Current industry practices do not demonstrate an interest amongst insurance companies to use genetic testing as an underwriting tool.⁶² It is important to note that insurance companies already have access to an individual's genetic information when they require the individual to provide a family medical history.

Insurance companies do request access to the results of any pre-existing personal genetic information.⁶³ This may change in the future as advances in technology make it both cost effective and easier for individuals to undergo genetic testing.⁶⁴ Currently, not enough information is known about the links between an individual's genes, lifestyle and future health. The use of genetic tests by the industry as a basis for decisions regarding insurance may be inappropriate.

In Canada, the insurance industry falls under provincial jurisdiction. In the common law provinces, the various statutes dealing with insurance are substantially similar as they are all drawn from the *1922 Uniform Insurance Act*. In Quebec, the only civil law province, the *Civil Code* creates a similar legal framework.

There is currently no legislation in Canada to specifically address the possibility of genetic discrimination in the context of private insurance contracts.⁶⁵ In addition, nothing currently exists to prevent genetic testing from being a prerequisite to obtaining private health or life insurance. Any legislation that regulates the insurance industry must be in compliance with the *Charter*.

5.6.6 Issues Arising in Other Contexts

As mentioned previously, discrimination based on genetic information could arise in a variety of other circumstances. For instance, genetic information could be used in the immigration law context in order to screen persons seeking to immigrate to Canada.

Some authors have suggested that there exists a possibility for discrimination in the health care sector as well.⁶⁶ Questions of what the government is willing to fund within the health care context may also give rise to issues of discrimination based upon genetic information.

In the family law context, questions respecting custody of, or the adoption of, children may also be influenced by the information obtained about parents through genetic testing.⁶⁷ Other potential areas of concern include military service and the ability to obtain financial services, such as access to credit.⁶⁸

⁵⁹ E. Oscapella, *supra* note 2 at 25.

⁶⁰ *Ibid.* at 13.

⁶¹ *Ibid.* at 25.

⁶² THiNC Health Inc., *supra* note 54 at 44.

⁶³ *Ibid.*

⁶⁴ *Ibid.*

⁶⁵ *Ibid.* at 49.

⁶⁶ N.M. Ries, *supra* note 42 at 21-22.

⁶⁷ N. Carnadin, "Genetic Information: The Domestic Legal Framework" (28 February 2003) [unpublished] at 68.

⁶⁸ See E. Oscapella, *supra* note 2 at 25.

5.6.7 Conclusion

In Canada, there appears to be no explicit statutory prohibition on discrimination based upon a predisposition to illness. Having said this, recent jurisprudence from the SCC supports the proposition that genetic predisposition would be caught under the rubric of disability.⁶⁹ These decisions emphasize that the concept of disability is not limited solely to biomedical conditions, but must also encompass societal perceptions and responses to such conditions. It has been recommended in the La Forest report that the definition of disability under federal human rights legislation be amended to include genetic predisposition to illness. While this recommendation arose during a review of the federal *Canadian Human Rights Act*, it could be extended to include provincial human rights legislation as well. This would extend protection from genetic discrimination to all Canadian jurisdictions and ensure consistency across them.

The use of genetic information in the areas of employment and insurance raises the possibility of discriminatory conduct. This risk extends to other areas including immigration, family law and access to health benefits. In this regard, the use of genetic information can threaten the basic human right of equality. In crafting an appropriate legal, social and policy response to these concerns, it is important that human rights principles are kept in mind.

5.7 Issue 2: Privacy

Privacy has been defined as “limited access to a person, the right of an individual to be left alone and the right to keep certain information from disclosure to other individuals.”⁷⁰ Privacy encompasses both the liberty and intimacy interests of individuals.⁷¹ There exist many concerns about safeguarding the privacy of genetic information, particularly as it touches on highly personal and sensitive information about individuals and their family members.⁷² Ongoing developments in technology create new challenges to the protection of information, including the protection of genetic information.

The concept of privacy is closely linked to confidentiality. Conceptually, however, they can, if respected, protect an individual in different ways. As noted above, privacy is about an individual not being required to provide certain

types of information about themselves to others.

Confidentiality, on the other hand, may be said to involve the prevention of information known about a person from being further disclosed to a third party or utilized for purposes not authorized by the individual whose information is at issue. So while privacy interests are about information not being revealed by others, confidentiality prevents information, once revealed, from further unauthorized disclosure. Both serve to protect the liberty and integrity interests of the individual.

This section will review the privacy and confidentiality issues that arise within the context of genetic information. One specific issue that will be addressed is whether or not individuals have the “right” to know or not know the genetic information of close family members. The possibility of family members having a right to know conflicts with an individual’s privacy interests, as well as their interest in having their genetic information kept confidential.

5.7.1 The International Context

The right to privacy and confidentiality is recognized in numerous international documents, both generally and in relation to genetic and health information. Article 17 of the *International Covenant on Civil and Political Rights* stipulates, “no one shall be subjected to arbitrary or unlawful interference with her or his privacy.”⁷³ The *UNESCO Declaration on the Human Genome and Human Rights* mandates that genetic information associated with an identifiable person and stored for any purpose must be kept confidential.⁷⁴ Similarly, the *UNESCO International Declaration on Human Genetic Data* encourages states to ensure that the privacy of individuals and the confidentiality of their genetic information. This *Declaration* provides that genetic information should not be disclosed to third parties except for important public interest reasons.⁷⁵

⁶⁹ *Boisbriand (City)*, *supra* note 43; and *Granovsky*, *supra* note 45.

⁷⁰ M.A. Rothstein, “Genetic Privacy and Confidentiality: Why They Are So Hard to Protect” (1998) 26 *Journal of Law, Medicine & Ethics* 198.

⁷¹ B.M. Knoppers, “Genetic Privacy: A Policy Approach” (15 April 2003) [unpublished] at 4.

⁷² N.M. Ries, *supra* note 42 at 25.

⁷³ *International Covenant on Civil and Political Rights*, 19 December 1966, 999 U.N.T.S. 171, art. 17 (entered into force 23 March 1976).

⁷⁴ *Supra* note 29. See Article 7 of the Declaration.

⁷⁵ *Supra* note 33. See Article 14 of the Declaration.

Regional documents also consider the issue of the right to privacy. For instance, the *Additional Protocol to the Convention on Human Rights and Biomedicine on the Prohibition of Cloning Human Beings*⁷⁶ states, “every one has the right to respect for private life in relation to information about his or her health”. The 2000 *Charter of Fundamental Rights of the European Union* recognizes that genetic privacy is a fundamental right.⁷⁷

5.7.2 The Comparative Context

Iceland has enacted legislation that treats genetic information as health information.⁷⁸ Iceland also stores personal genetic information in genetic data banks and its law presumes that this information has been stored by consent unless an individual has explicitly opted out. Essentially, Iceland’s legislation authorizes the establishment of a centralised database of non-identifiable personal data to promote medical knowledge.⁷⁹

Iceland’s commodification of its “genetic resources” is not without controversy.⁸⁰ For one, the genetic database has been initiated by a commercial firm, in cooperation with the government, creating the possibility of a licensing system which allows for a license to be granted to only one party, thus creating a virtual monopoly.⁸¹ Another concern raised has been the sufficiency of the measures taken to make the information non-identifiable thereby protecting the privacy of the individuals whose information is stored.⁸² The commercialization is particularly controversial as it allows a private entity to profit from the personal genetic and medical histories of the Icelandic people.⁸³ Certainly, Iceland’s model for protecting genetic information represents a unique approach compared with other states.

5.7.3 The Canadian Context⁸⁴

In Canada, privacy is protected through a variety of mechanisms including constitutional law, federal and provincial legislation, and the common law. The *Charter* is an important legal safeguard for the protection of privacy in Canada. Again, however, the *Charter*’s applicability is limited generally to instances involving government action. Moreover, as will be demonstrated below, the *Charter*’s protection of privacy is predominantly limited to areas where there exists a “reasonable expectation of privacy.”

The Charter

On its face, the *Charter* does not guarantee a right to privacy: rather, privacy interests are encompassed within the various rights specifically protected under the *Charter*, and in particular s. 8.⁸⁵ There is, however, a residual source of privacy protection found under s. 7. While the state can intrude on these rights by virtue of s. 1 of the *Charter*, stringent conditions must be met before this section will limit a constitutionally protected right.⁸⁶

Section 8 of the *Charter* states: “[e]veryone has the right to be secure against unreasonable search or seizure.” The protection afforded by s. 8 predominantly arises in the criminal context. The role that s. 8 plays is to protect against unjustified state intrusions on individuals’ reasonable expectation of privacy.⁸⁷ In determining whether s. 8 will operate to protect a privacy interest, regard must be had to the object or information that is searched or seized.⁸⁸ A reasonable expectation of privacy, in relation to the object or information must be established in order for the s. 8 right to be triggered.⁸⁹ Depending on the context, expectations of privacy will vary. Numerous court decisions have discussed the protection of privacy under s. 8.

In *Canadian Aids Society v. Ontario*,⁹⁰ Wilson J., of the trial division, had opportunity to discuss the protection to be

⁷⁶ *Additional Protocol to the Convention on Human Rights and Biomedicine on the Prohibition of Cloning Human Beings*, 12 January 1998, E.T.S. No. 168 (Council of Europe).

⁷⁷ *Charter of Fundamental Rights of the European Union*, 18 December 2000, Official Journal of the European Communities C 364/1.

⁷⁸ *An Act on Protection of Individuals with Regard to the Processing of Personal Data No 77/2000*.

⁷⁹ M. Letendre, C. Sallée *et al.*, *supra* note 19 at 16.

⁸⁰ *Ibid.* at 6.

⁸¹ L. Nelson, “The Icelandic Health Sector Database, Legal and Ethical Considerations” in T.A. Caufield and B. Williams-Jones, eds., *The Commercialization of Genetic Research: Ethical, Legal, and Policy Issues* (New York: Kluwer Academic/Plenum Publishers, 1999) 111 at 111.

⁸² *Ibid.* at 121.

⁸³ *Ibid.* at 124.

⁸⁴ This section draws heavily upon the summary of N.M. Ries, *supra* note 42, and the author is indebted for this work, particularly the summary of the protections afforded by the *Charter*.

⁸⁵ N.M. Ries, *supra* note 42 at 25.

⁸⁶ E. Oscapella, *supra* note 2 at 10.

⁸⁷ *Hunter v. Southam Inc.*, [1984] 2 S.C.R. 145 at 160 (hereinafter “*Hunter*”).

⁸⁸ N. Carnadin, *supra* note 67 at 12.

⁸⁹ *Ibid.*

⁹⁰ *Canadian Aids Society v. Ontario* (1995) 25 O.R. (3d) 388 (Gen. Div.), affirmed (1996), 31 O.R. (3d) 798 (C.A.), leave to appeal to S.C.C. refused (1997), 107 O.A.C. 80.

given to information obtained from blood samples that were voluntarily donated to the Red Cross. The Court held:

The samples were given voluntarily. Consent, however, was not given to release the information in the blood to the public health authorities. There was a reasonable expectation of privacy when the donation was made. Donors would not have expected to be subjected to mandatory testing and public reporting ten years after making their donation.

The Ontario Court of Appeal affirmed this decision with little discussion.

In *R. v. Plant*,⁹¹ the SCC noted:

In fostering the underlying values of dignity, integrity and autonomy, it is fitting that s. 8 of the *Charter* should seek to protect a biographical core of personal information which individuals in a free and democratic society would wish to maintain and control from dissemination to the state. This would include information which tends to reveal intimate details of the lifestyle and personal choices of the individual.⁹²

This passage tends to support the proposition that genetic information would be protected under the *Charter* as part of a person's "biographical core". The *Charter's* protection would be triggered if the government committed an intrusion of the individual's reasonable expectation of privacy.

Similar language can be found in *R. v. Dymnt*,⁹³ a case dealing with the collection of a blood sample by a physician who then turned the sample over to the police. In this decision, the SCC held that a patient has a privacy interest in his blood sample, an "intimately personal" substance.⁹⁴ Nonetheless, this information would only be protected by s. 8 of the *Charter* provided there was a reasonable expectation of privacy connected to the information.

In *Hunter*, the Court stated:

The guarantee of security from unreasonable search and seizure only protects a reasonable expectation. This limitation on the right guaranteed by s. 8, whether it is expressed negatively as freedom from

"unreasonable" search and seizure, or positively as an entitlement to a "reasonable" expectation of privacy, indicates that an assessment must be made as to whether in a particular situation the public's interest in being left alone by government must give way to the government's interest in intruding on the individual's privacy in order to advance its goals, notably those of law enforcement.⁹⁵

Finally, in *Dymnt*, the Court held:

[g]rounded in man's physical and moral autonomy, privacy is essential for the well-being of the individual. For this reason alone, it is worthy of constitutional protection, but it also has profound significance for the public order. The restraints imposed on government to pry into the lives of citizens go to the essence of the democratic state.⁹⁶

Section 7 of the *Charter* provides: "[e]veryone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice". Though not the primary source of privacy protection under the *Charter*, it does provide for some residual protection. The SCC has had the opportunity to discuss this section as it applies to the protection of privacy on various occasions.

In *R. v O'Connor*,⁹⁷ L'Heureux-Dube J. noted:

Although it may appear trite to say so, I underline that when a private document or record is revealed and the reasonable expectation of privacy therein is thereby displaced, the invasion is not with respect to the particular document or record in question. Rather, it is an invasion of the *dignity* and self-worth of the individual, who enjoys the right to privacy as an essential aspect of his or her *liberty* in a free and democratic society. [emphasis added]⁹⁸

⁹¹ [1993] 3 S.C.R. 281.

⁹² *Ibid.* at 293.

⁹³ [1988] 2 S.C.R. 417.

⁹⁴ *Ibid.* at 432.

⁹⁵ *Hunter*, *supra* note 87 at 159-160.

⁹⁶ *Dymnt*, *supra* note 93 at 427-428.

⁹⁷ [1995] 4 S.C.R. 411.

⁹⁸ *Ibid.* at 487.

The Court's discussion in *R. v. Mills*⁹⁹ is also informative:

This Court has most often characterized the values engaged by privacy in terms of liberty, or the right to be left alone by the state... This interest in being left alone by the state includes the ability to control the dissemination of confidential information...

These privacy concerns are at their strongest where aspects of one's individual identity are at stake, such as in the context of information "about one's lifestyle, intimate relations or political or religious opinion."¹⁰⁰

The jurisprudence to date from the SCC demonstrates that while there is no explicit stand alone right to privacy under the *Charter*, privacy interests may be afforded protection under ss. 7 and 8. This is more readily the case with s. 8 protection against unreasonable search and seizure. It must be remembered, however, that the *Charter's* protection extends to the actions of government and not private actors. Moreover, it must be demonstrated, for the s. 8 rights to be triggered, that the individual had a reasonable expectation of privacy. In addition, the jurisprudence discussed above and the corresponding rights articulated therein have arisen primarily in the criminal context. These considerations must be born in mind when looking at whether the protections afforded under the *Charter* would apply to genetic information in the non-criminal context.

Privacy Legislation

The collection, use, disclosure and retention of personal information by governments at the federal and provincial levels is regulated in Canada through privacy legislation. At the federal level, the *Privacy Act* provides the legislative framework which protects information in the hands of the federal government.¹⁰¹ Personal information is defined under the *Act* as "information about an identifiable individual that is recorded in any form."¹⁰² Examples of personal information include an individual's fingerprints and blood type, as well as their medical history. The scope of personal information protected by the *Act* has been interpreted broadly. In *Dagg v. Canada (Minister of Finance)*,¹⁰³ the SCC held:

With these broad principles in mind, I will now consider whether the information requested by the

appellant constitutes personal information under s. 3 of the *Privacy Act*. In its opening paragraph, the provision states that "personal information" means "information about an identifiable individual that is recorded in any form including, without restricting the generality of the foregoing". On a plain reading, this definition is undeniably expansive...the language of this section is 'deliberately broad' and 'entirely consistent with the great pains that have been taken to safeguard individual identity.' Its intent seems to be to capture any information about a specific person, subject only to specific exceptions.¹⁰⁴

The SCC endorsed a broad approach to determine what constitutes personal information under the federal privacy legislation.¹⁰⁵ As a result, this approach might include genetic information.

The *Privacy Act* contains a Code of fair information practices that deals with the collection, retention, accuracy, use and disclosure of personal information by government institutions subject to the *Act*. The Code requires a government institution to:

- collect only the personal information that relates directly to an operating program or activity of the institution (s. 4);
- collect the personal information from the individual to whom it relates and inform the individual of the purposes of the information unless doing so might result in the collection of inaccurate information or defeat the purpose of prejudice the use for which the information is to be collected (s. 5);

⁹⁹ [1999] 3 S.C.R. 668.

¹⁰⁰ *Ibid.* at 721-722.

¹⁰¹ The *Privacy Act* applies to government institutions listed in the Schedule.

¹⁰² *Supra* note 24. See s. 3.

¹⁰³ [1997] 2 S.C.R. 403.

¹⁰⁴ *Ibid.* at para. 68 and 69. While this passage was expressed in the minority judgement, the majority expressly indicated agreement with this approach to the interpretation of the *Act* (at para. 1).

¹⁰⁵ This broad interpretation has since been confirmed by the SCC in *Lavigne v. Canada (Office of Commissioner of Official Languages)* (2002) SCC 53 and in *Canada (Information Commissioner) v. Canada (Commissioner of the RCMP)* (2003) SCC 8.

- retain the personal information that has been used for an administrative purpose long enough to allow the individual a reasonable opportunity to obtain access as specified in the regulations (s. 6);
- ensure the information that is used for an administrative purpose is as accurate, up-to-date and complete as possible (s. 6);
- unless the person consents otherwise, use the personal information for the purpose for which it was obtained, a consistent use, or for a purpose for which it can be disclosed under section 8 of the *Privacy Act* (s. 7);
- not disclose the personal information without the individual's consent unless one of the thirteen authorized disclosures under the *Privacy Act* applies (s. 8).

In addition to the *Privacy Act*, the federal *PIPEDA* establishes a national standard for data protection in all sectors and the extension of fair information practices to the private sector in Canada.¹⁰⁶ *PIPEDA* acknowledges that “health information” is personal information. As N. Carnadin describes:

Section 2(1) defines “personal health information” for application in Part 1, the protection of personal information in the private sector. “Personal health information” concerns an individual, whether living or deceased, and includes information about the following: physical or mental health, the provision of health services as well as any information collected during the course of providing such services, the donation of any body part or bodily substance and any related information or testing as well as incidentally collected information. While *PIPEDA* does not use the term “genetic information” in the definition, it is clear that the comprehensive definition of personal health information includes protection for an individual's genetic information.¹⁰⁷

PIPEDA requires organizations, unless one of the specific exceptions applies, to obtain the individual's consent when they collect, use or disclose personal information.

The *Assisted Human Reproduction Act*¹⁰⁸ (“AHR Act”) contains a privacy scheme to protect personal health

information, including genetic information, collected by fertility clinics and retained by the future AHR Agency. The AHR Act regulates the collection, retention, use, and disclosure of the personal health reporting information of sperm and ova donors, offspring created with donated gametes, and persons using donated gametes to create their families. In addition to the AHR Act, there are other federal laws that protect the privacy interests of individuals with respect to their genetic information.

In addition, the protection of privacy at the provincial level is accomplished through freedom of information and protection of privacy legislation. Each provincial statute contains a definition of personal information, although there is no specific reference to “genetic information,”¹⁰⁹ Despite this, the inclusion of information about an individual's blood type, fingerprints or inheritable characteristics, as well as information about a person's health, indicates that genetic information is included in the definition of personal information.¹¹⁰

Additionally, four provinces have created, through their provincial privacy legislation, a statutory tort of invasion of privacy.¹¹¹ The tort allows for an individual to seek legal redress, without proof of damage, when their privacy has been violated without their permission.¹¹² The tort addresses invasions of privacy committed in the provincial private sector.¹¹³

5.8 Issues Arising with the “Right” to Know/ Not Know

The idea that an individual has an interest in the results of her own genetic testing is obvious. Indeed, the very fact that she has consented to the test implies that she has the right to learn of the results. Arguably, the same result

¹⁰⁶ *ThiNC Health Inc.*, *supra* note 54 at 19. This Act sets out ground rules for how private-sector organizations may collect, use and disclose personal information in the course of their commercial activities (see section 4).

¹⁰⁷ N. Carnadin, *supra* note 67 at 22.

¹⁰⁸ *An Act Respecting Assisted Human Reproduction and Related Research*, Third Session, thirty-seventh Parliament, 52-53 Elizabeth II, 2004. Sections of the Act were proclaimed in force on April 22, 2004.

¹⁰⁹ N. Carnadin, *supra* note 67 at 28-29.

¹¹⁰ *Ibid.* at 29.

¹¹¹ British Columbia, Saskatchewan, Manitoba and Newfoundland and Labrador have created this statutory tort.

¹¹² N. Carnadin, *supra* note 67 at 34.

¹¹³ *Ibid.* at 39.

would hold in the case of an individual who was required to undergo genetic testing, for instance in the case where it was a pre-requisite for employment. Individuals who do not wish to know their genetic information should not be informed of the results. It is likely that requiring or mandating such testing would violate principles of individual autonomy.¹¹⁴ Indeed, article 10 of the UNESCO International Declaration on Human Genetic Data states that individuals have the right to decide whether or not to be informed about the results of tests done for medical or scientific research purposes.¹¹⁵

The notion of a “right” to know or not know becomes more contentious when close family members claim such a right with respect to the results of one member’s genetic tests. Does an individual, whose close family member has been tested and found to have a predisposition to a genetic condition, have a legal “right” to be informed of that family member’s test results? Further, does this answer change if one party is a minor?¹¹⁶ Should an individual have a legal right or rather, would it be more appropriate to recognize, as a matter of public policy, that in certain instances an individual should be entitled to learn of the test results of a close family member?

5.8.1 The International Context

The issue of whether individuals should have access to the test results of close family members has garnered attention at the international level, and in other jurisdictions.

The World Medical Association, as well as the Human Genome Organization and World Health Organization have suggested that a blood relative should only have access to an individual family member’s genetic information under exceptional circumstances.¹¹⁷ This information could only be disclosed under exceptional circumstances if the individual whose genetic information is sought is deceased.¹¹⁸ Exceptional circumstances would include when the information could save the life of a relative or prevent serious harm.¹¹⁹ The World Medical Organization has articulated this entitlement to be provided the genetic information of a family member as a “right” though strictly speaking the right is not legally enforceable. In this sense, the right articulates a moral imperative.

UNESCO’s *International Declaration on Human Genetic Data* suggests that genetic data of an individual should not be disclosed or made accessible to third parties. However, it does recognize exceptions to this position. Article 14(b) reads:

Human genetic data, human proteomic data and biological samples linked to an identifiable person should not be disclosed or made accessible to third parties, in particular, employers, insurance companies, educational institutions and the family, except for an important public interest reason in cases restrictively provided for by domestic law consistent with the international law of human rights or where the prior, free, informed and express consent of the person concerned has been obtained provided that such consent is in accordance with domestic law and the international law of human rights. The privacy of an individual participating in a study using human genetic data, human proteomic data or biological samples should be protected and the data should be treated as confidential.¹²⁰

Thus disclosure of genetic data is only permitted if there has been prior informed consent or if there is an important public reason that is provided for by domestic law and is in accordance with the principles of international human rights. The Declaration does not create a “right” per se to the genetic information of close family members.

5.8.2 The Comparative Context

In Australia, the *National Health and Medical Research Council’s National Statement on Ethical Conduct in Research Involving Humans* indicates that consent is required prior to disclosure of a family member’s genetic information in all but two situations: (a) where the individual is dead, the information can be disclosed to the deceased’s spouse or

¹¹⁴ E. Oscapella, *supra* note 2 at 21.

¹¹⁵ *Supra* note 33. See article 10.

¹¹⁶ E. Oscapella, *supra* note 2 at 22.

¹¹⁷ See M. Letendre, C. Sallée *et al.*, *supra* note 19 at 74-75.

¹¹⁸ *World Medical Association Declaration on the Rights of the Patient*, September/October 1981, WMA, 34th World Medical Assembly and amended by the 47th General Assembly. See article 8.

¹¹⁹ M. Letendre, C. Sallée *et al.*, *supra* note 19 at 75.

¹²⁰ Article 14 (b), *supra* note 29.

senior next-of-kin; and (b) when family members are at high risk of a serious disorder.¹²¹ The Australian model demonstrates an approach to disclosure that is premised on policy rather than a legal right.

The situation is more restricted in the U.K., where family access to genetic information about an individual is confidential, subject to the consent of the party whose genetic information is in question.¹²² There is no explicit legislation providing a “right” to know. The Human Genetics Commission has indicated that in some instances family members may have a right to know, thus while there is no legal right to know there may be, in certain instances, a moral right.¹²³

The U.S. has legislated in this area permitting disclosure of an individual’s medical information without consent in limited situations including emergencies, when a provider is required by law to treat the individual, or when there are substantial communication barriers.¹²⁴ As such, access to genetic information is not guaranteed as of right.

In India, the Indian Council of Medical Research considers that family members hold a responsibility to inform those who are at high risk of disease.¹²⁵ Thus, in India the response is framed within a strictly ethical framework rather than a legal one.

Finally, in France discussion is underway to determine if it would be appropriate to pass a law to oblige a person to disclose their genetic information to their family circle once they have discovered a predisposition for disease.¹²⁶ Of all the jurisdictions discussed, this approach would be the most intrusive on an individual’s right to privacy.

The international and comparative contexts demonstrate that there is no legal “right” to know the genetic information of a close family member. The approach taken by some jurisdictions of allowing limited access to genetic information of close family members appears to have been based on public policy reasons, rooted in moral imperatives, rather than legal rights. By and large, the presumption is that an individual’s genetic information is to be kept private, with disclosure permitted as an exception in limited circumstances based public policy reasons, such as health and safety.

5.8.3 The Canadian Context

Canada does not provide individuals with the right to obtain the genetic information of a family member that may disclose a predisposition to illness. The legislative framework in Canada, which includes privacy legislation at all levels of government and the *Charter*, does not explicitly provide such a right. Similarly, there does not appear to be any case law addressing this issue.

The AHR Act permits the disclosure of health reporting information related to a donor of human reproductive material (or an *in vitro* embryo) to individuals using the donor’s genetic material in an assisted human reproduction procedure, to any offspring conceived using the donor’s genetic material or to descendants of the person so conceived. The AHR Act, however, does not permit the disclosure of the identity of the donor without his or her written consent.¹²⁷ Essentially, this provision creates a very limited statutory “right” to know for persons using or conceived with donated reproductive material or an *in vitro* embryo.

No Canadian jurisdiction has legislation imposing a legal obligation on individuals or health professionals to warn other family members of the results of genetic testing.¹²⁸ Mandating such an approach, strictly speaking, would not create a right for individuals to know, but rather it would impose a duty on individuals to disclose. Such a legal obligation would implicate s. 8 of the *Charter* and need to respect its dictates.

Legislation in Canada does not openly provide for a deontological approach to disclosure of personal information, nor does it support a “right” to know. Having said

¹²¹ M. Letendre, C. Sallée *et al.*, *supra* note 19 at 76.

¹²² *Ibid.* at 79.

¹²³ *Ibid.*

¹²⁴ *Standards for Privacy of Individually Identifiable Health Information*, Code of Federal Regulations, Title 45, CFR 164.506, Washington D.C., August 14, 2002, online: http://www.hhs.gov/general/web/webapps/sitelink/site.asp?link_hhs=%20; <http://www.cms.hhs.gov/hipaa/hipaa2/default.asp>.

¹²⁵ M. Letendre & C. Sallée *supra* note 19 at 82-83.

¹²⁶ “MCCNE advice on the obligation to inform one’s family of genetic risks” *Gèneéthique* 46 (October 2003) online: <http://www.geneethique.org>. Accessed Jan. 2004

¹²⁷ *Supra* note 108 at s. 18(3).

¹²⁸ B.M. Knoppers, *supra* note 71 at 18.

this, in some instances the legislation allows for disclosure as a matter of public policy.

For instance, Alberta's privacy legislation does contemplate disclosures of personal information if there are significant risks to the health and safety of the public, a particular group or an individual.¹²⁹ Similarly, Canada's *Privacy Act* permits disclosure when the public interest clearly outweighs any invasion of privacy that could result from such disclosure.¹³⁰ These examples do not provide for a right per se but rather mandate instances where, for public health reasons, disclosure of personal information is justified.

5.8.4 Conclusion

An individual currently has no legal right in Canada to be provided the genetic information of a close family member.¹³¹ Further, an individual has no legal right in Canada to be informed that they may be genetically predisposed to illness simply because a close family member has been tested and shows susceptibility. Rather, it would appear that an individual's genetic information would be protected under constitutional and privacy law in Canada and that any unauthorized disclosure, even if it is to a close family member, may give rise to legal action.

The approach in other jurisdictions and internationally varies. The Australian and U.S. models tend to place the autonomy of the individual over that of the family members who claim a right to know. The proposed French approach places the right of family members to know as primary.

Clearly, human rights are engaged in this issue. At present, Canadian law has not dealt with the issue of the "right" to know. It remains to be seen whether this interest in knowing will develop into a free standing legal right.

5.9 Issues Arising Around Confidentiality

The implications arising from the discussion above are that, generally speaking, an individual has the right to have their genetic information kept confidential. No disclosure to family members is permitted. *Charter* jurisprudence concerning the right to privacy and the

interests at stake, notably autonomy, liberty and dignity, suggests that individuals would have their rights to privacy and confidentiality protected if these rights are threatened by government action. Beyond this context, there are some additional safeguards in Canada to ensure that genetic information is kept private and confidential. The protections afforded arise in a variety of contexts including criminal law, healthcare and the collection or disclosure of information in the commercial context.

Under the *Criminal Code* (the "Code"),¹³² DNA samples may be obtained by warrant for a number of designated offences. However, the Code also mandates that any DNA information obtained can only be used for the purposes of forensic DNA analysis.¹³³ Indeed, it is a criminal offence to use the DNA samples for any purpose other than those specified under the Code.¹³⁴

In the context of healthcare, there is a common law duty of confidentiality. In *McInerney v. MacDonald*,¹³⁵ the SCC held that the special relationship between a doctor and his or her patient gives rise to the duty of the doctor to act with utmost good faith and loyalty and to hold information received from or about a patient in confidence.¹³⁶ This duty protects individuals from disclosure of their personal information for any unauthorized purposes, including genetic information, in all but exceptional circumstances.

There is no similar common law duty in the context of genetic information held by commercial organizations. In this respect federal, provincial and territorial legislation governing the collection, use and disclosure of personal health information applies. Part 1 of *PIPEDA* covers personal information, including personal health information,

¹²⁹ Alberta *supra* note 27. See ss. 17(1) and 32(1).

¹³⁰ *Supra* note 24. See s. 8(2)(m)(i).

¹³¹ B.M. Knoppers, *supra* note 71 at 19. Moreover there appears no legal duty to warn. Knoppers has suggested that at this time "any "duty" to warn at-risk family members be a matter of professional ethics and not [be] enshrined in legislation." She does note, however, that access to data of deceased family members should be legislated.

¹³² R.S.C. 1985, c. C-46. The provisions dealing with DNA evidence are found at ss. 487.04- 487.092.

¹³³ *Ibid.* s. 487.08(1).

¹³⁴ *Ibid.* s. 487.08 (4).

¹³⁵ [1992] 2 S.C.R. 138.

¹³⁶ *Ibid.* at paras 20-22.

collected, used or disclosed by organizations within the private sector in the course of a commercial activity.

As of January 1, 2004, and relying on the federal government's trade and commerce power (found in s. 91(2) of the *Constitution Act, 1867*), *PIPEDA* applies to any organization engaged in the collection, use or disclosure of personal information, including health information, in the course of a commercial activity. If, however, the province has in place substantially similar legislation and it has been exempted by an Order of the Governor in Council, the application of *PIPEDA* to the collection, use, and disclosure of personal information within that province would be suspended. To date, only Quebec's *An Act Respecting the Protection of Personal Information in the Private Sector* has been deemed to be substantially similar pursuant to such an Order in Council (see Organizations in the Province of Quebec Exemption Order P.C. 2003-1842, 19 November, 2003). Therefore, only organizations within Quebec are exempt from the operation of *PIPEDA* as of January 1, 2004.

It should be noted that *PIPEDA*, while protecting the confidentiality interest of the individual pertaining to his or her personal health information, is limited to information obtained through "commercial activities."

5.9.1 Conclusion

In Canada, an individual's interest in the confidentiality of her or his personal information, including having one's genetic information kept confidential, is afforded protection under the *Charter*, the common law and other legislation. The protection of confidentiality afforded through the law makes the fulfillment of basic human rights possible, including the right to be protected from arbitrary interference with one's privacy. The WG has recommended, given the important role genomics plays in society, that policy development take place relating to the collection, handling, storage, use and management of federal government holdings of human genetic information.

5.10 Gaps in the Human Rights Framework

As noted above, the La Forest Report recommended that a genetic predisposition to a condition be explicitly afforded protection under Canadian human rights legislation. While it has been suggested above that recent jurisprudence in Canada may be sufficient to protect individuals from discrimination based on genetic information, there is no explicit protection against discrimination on the basis of genetic information. In this regard, a gap possibly exists in the law's ability to protect in the area of genetic information and discrimination.

Within the context of insurance, the use of genetic information by insurers to make decisions about providing insurance may impact on the ability of individuals to access health resources. Requiring individuals to provide insurance companies known genetic information may result in people refusing to undergo genetic testing. This, in turn, may adversely impact the health of individuals who might otherwise be able to receive treatment for their conditions. Genetic information and its use by the insurance industry can engage numerous human rights issues. As with the area of employment, there currently exists little jurisprudence dealing with this issue. It will be important to approach these areas with traditional human rights principles in mind, such as equality, security of the person and autonomy.

The potential for discrimination exists in a much broader sphere than the areas of employment and insurance. Some of the areas identified above include family, immigration and health law. The fact that so little attention has been paid to the topic of genetic information and its interplay with these areas of law also, by necessity, means that our understanding of the human rights issues in these areas remains largely rudimentary. Attention will be required in these areas in the future.

The issue of whether a close family member has the "right" to know the genetic information of another family member who learns that they are genetically predisposed to a condition has not been clearly articulated in Canadian law. This issue encompasses human rights concerns which may be addressed as a matter of public policy, or alternatively through a rights, or duty based approach.

5.11 Conclusion

The human rights issues relating to genetic information domestically and internationally will continue to arise in accordance with the advancement of our knowledge and subsequent use of genetic information in society. Clearly, our understanding of basic human rights such as the right to privacy, equality and security of the person will expand in recognition of the greater role that genetic information occupies in society. Additionally, other human rights as reflected in international documents, such as the right to benefit from scientific knowledge and the right to health will undoubtedly develop in accordance with our understanding of genetic information.

In large part, the rights evolution will develop in accordance with how societies choose to respond to the complex social and ethical issues that advancements in genomics will bring. At present, human rights discourse in this area is in its infancy. Yet, as this chapter has shown, there is recognition that the availability and use of genetic information does engage equality and privacy interests of individuals which may serve as useful starting points in the continuing development of this area.