

Genetics, Privacy and Discrimination

Prepared for

The Canadian Biotechnology Advisory Committee
Project Steering Committee
On the Genetic Privacy

By

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October 31, 2000

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A Survey Prepared for the Canadian Biotechnology
Advisory Committee
Project Steering Committee
on Genetic Privacy

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October 31, 2000

Table of Contents

Executive Summary	1
Introduction	4
Part I: The Science.....	6
1. What Genetic Technology Can Reveal.....	6
2. Uses of Genetic Information	7
Part II: Legislative Schemes Dealing with Genetic Privacy and Discrimination.....	8
1. The General Legal Framework	8
a. Constitutional Law	8
b. Federal and Provincial Data Protection Laws.....	8
c. Provincial Health Information Legislation.....	9
d. Human Rights Codes.....	10
e. Insurance Law	11
f. Statutory Torts.....	12
g. Professional Codes	12
h. Laws Protecting Against Physical Intrusion.....	13
i. Possible Quasi-Constitutional Protection: the <i>Privacy Rights Charter</i> (Bill S-27).....	13
2. Examples of Canadian Laws and Other Initiatives Directed Specifically at Genetics Issues	14
a. <i>Bill C-47: Human Reproductive and Genetic Technologies Act</i>	14
b. Research Ethics.....	14
c. Report of the Privacy Commissioner of Canada, <i>Genetic Testing and Privacy</i>	15
d. The Canadian Genome Analysis and Technology Program (CGAT)	15
e. House of Commons Standing Committee on Human Rights and the Status of Persons with Disabilities	15
3. International Initiatives	16
a. The Proposed <i>Genetic Privacy Act</i>	16
b. Council of Europe <i>Convention on Human Rights and Biomedicine 1997</i>	16
c. <i>Universal Declaration on the Human Genome and Human Rights</i> (UNESCO 1997).....	17

d.	Other International Instruments	17
Part III: The Issues		18
1. Overriding Issues		18
a.	Tension Between the Potential Benefits and Harms of Genetic Technology	18
b.	Is Genetic Information an Exceptional Form of Personal Information?	18
c.	The Right Not to Know.....	18
d.	Secret and Private Testing	19
e.	Disclosure to Biological Relatives.....	20
f.	Discrimination on the Basis of Perceived Disability	20
g.	A Residual Right of Genetic Privacy?.....	20
2. Issues Relating to Specific Situations		21
a.	Human Reproduction	21
b.	Employment.....	21
c.	Testing to Determine Eligibility for Services Such as Insurance and Credit	22
Part IV: Recommendations and Conclusion		24
1. The Central Dilemma		24
2. Addressing the Issues		24
a.	Education.....	24
b.	Control on Further Dissemination of Genetic Information.....	24
c.	Genetics-Specific or General Legislation?	26
d.	Other Measures	27
3. Conclusion		28

Executive Summary

Genetic information about individuals – personal genetic information – has many current and potential uses: to assist in predicting, diagnosing, treating and preventing health conditions; to assist with reproductive decisions; to decide suitability for employment; to assess the health consequences of exposure to workplace contaminants – for example, radiation; to assess eligibility for services such as insurance and credit; as an identification tool in criminal investigations; to advance medical research; to verify gender in sports competitions; to determine paternity; and to assess the susceptibility of ethnic groups to genetically-tuned biological weapons.

The relatively recent advent of “molecular genetics” has increased the number of physical and behavioural characteristics that may be revealed by genetic testing. This in turn has heightened privacy concerns and fears of discrimination based on genetic “makeup.” That discrimination could take several forms – rejection for employment, restricted access to credit or insurance, and even discriminatory treatment in government programs dealing with reproduction and education.

Western countries generally have enacted little legislation dealing *specifically* with genetic privacy and discrimination. However, the list of laws and proposed laws applying specifically to genetics is growing, particularly in the United States and mainly in three areas – insurance, employment and criminal forensics.

In Canada, apart from criminal legislation on using DNA in criminal investigations, most provisions affecting genetic privacy and discrimination are found in laws of more general application. They appear in constitutional law, laws governing professional confidentiality, an emerging set of provincial laws dealing with health information, data protection (privacy) and human rights laws, statutory torts, and the criminal law (protections against physical intrusions). Many of these general laws were drafted without genetics in mind. Still, they provide a substantial, if incomplete, legal framework for handling personal genetic information.

Attempts to protect genetic privacy have also been made at the international level, such as through the 1997 European *Convention on Human Rights and Biomedicine* and the *Universal Declaration on the Human Genome and Human Rights* (UNESCO, 1997). Other more general international instruments are also relevant. These include research guidelines and conventions dealing with human rights generally.

General Issues

Tension Between the Potential Benefits and Harms of Genetic Technology: At present, many benefits of genetic science remain theoretical. However, the misuse of genetic information about individuals has already led to genetic discrimination, sometimes about overt genetic characteristics such as skin colour or gender, and other times about genetic traits discoverable only through testing – sickle cell anemia, for example.

Is Genetic Information an Exceptional Form of Personal Information? Debate continues about whether genetic information is somehow “exceptional”, requiring different, perhaps more cautious and protective treatment than other types of personal information.

The Right Not to Know: Respect for individual autonomy can be used as the basis to argue that individuals should not be forced to acquire genetic information about themselves. Such knowledge could be catastrophic – such as learning, against one’s wishes, that one has the gene that causes Huntington disease. As well, there is debate whether minors have or should have an equivalent right not to know, or whether their guardians should be permitted to obtain information that the minors themselves might not later want?

Secret and Private Testing: Individuals may soon be able to identify a number of genetic traits through commercially available testing kits. These kits will inevitably invite the surreptitious testing of others. Even if not used surreptitiously, the very availability of these kits to the general public may encourage misuse – for example, to defraud insurance companies.

Disclosure to Biological Relatives: Test results about a person may identify genetic traits of biological relatives. There is considerable debate about whether a duty or ethical obligation exists on professionals or individuals to share useful genetic information with biological relatives.

Discrimination on the Basis of Perceived Disability: Case law and legislation have extended the protection against discrimination on the basis of disability to cases of perceived disability. Thus, the potential for discrimination on the basis of perceived disability is significantly reduced. However, the extent to which human rights legislation protects against discrimination because of a possible *future* genetically linked disability remains unclear.

A Residual Right of Genetic Privacy? Even if legislation, codes, ethical standards and other instruments were to provide generous confidentiality protection, some argue that there is nonetheless a residual right to say “no” to further uses of one’s genetic information. This issue is most germane in the context of research.

Specific Areas of Concern

Human Reproduction: Governments will inevitably be drawn to programs that prevent the birth of children with expensive genetic “disabilities.” Subsidiary issues also arise, among them how to prevent further dissemination of genetic information acquired by private reproductive clinics, and rights, if any, of children conceived as a result of a sperm or egg donation to learn the identity, or at least the genetic background, of the donor, and the potentially conflicting rights of the donor to confidentiality.

Employment: Employers may want genetic information about employees or job applicants. If the burden of health care costs shifts to the private sector, Canadian employers may become even more interested in hiring only the healthiest employees.

Testing to Determine Eligibility for Services Such as Insurance and Credit:

Genetic information may further separate those who have access to insurance, credit and other services from those who, because of their genetic makeup, do not.

Conclusions

The possible use of personal genetic information against individuals may justifiably stifle acceptance of further genetic inquiry. Failure to protect privacy and prevent discrimination therefore risks greatly diminishing the potential for genetics to improve health care.

The key to benefitting from genetic information while avoiding its drawbacks lies in controlling use of the information beyond the health care of the individual to whom the information relates. Regulation and, in some cases, prohibitions, on secondary uses of personal information are indispensable once personal genetic information has been collected. DNA collected and analyzed for health care purposes should not automatically be available for further uses, even research, if the DNA can be linked to an identifiable individual.

The ultimate protection, however, may often lie in more strictly limiting the *initial* collection of personal genetic information. For example, the greatest protection against state interference with human reproduction will come from keeping personal genetic information from the state in the first place.

General laws governing personal health information can often protect genetic information, although sometimes these general laws themselves are inadequate. However, genetic information brings new intensity to the need to protect personal health information. Legislation to address specific issues relating to genetic testing maybe required to supplement existing legislation. Legislation dealing with the taking of DNA from criminal suspects and the establishment of DNA databanks relating to convicted offenders must be carefully monitored to prevent an unwarranted enlargement of its scope.

Public education is essential to protect genetic privacy and prevent discrimination. Governments in particular have a duty to explain the uses of genetic information and their possible impact on society.

Genetics, Privacy and Discrimination

Introduction

Advances in genetic science give rise to many concerns – among them the violations of privacy inherent in collecting and analyzing genetic material. The possible further consequence of these violations, and the consequence that many fear most, is genetic discrimination – discrimination on the basis of one’s genetic “makeup.”

Discrimination may take any number of forms – rejection for employment, or the offer of lesser employment, loss of access to credit or insurance, or access only under extraordinary conditions and at extraordinary expense, and even discriminatory treatment in the application of government social policies relating to reproduction and education. The unwanted collection and release of genetic information may also interfere with personal relationships. A potential marriage partner may reject someone with a genetic risk of contributing to a “defective” child.

Above all, the promise of genetics for improved health and health care may be severely compromised unless privacy and discrimination issues are addressed. For example, a 1998 survey conducted for the US National Center for Genome Resources found that almost two-thirds of the respondents said they probably or definitely would not take genetic tests if health insurers or employers could get access to the results.¹ The possibility that genetic information will be used to the disadvantage of individuals, rather than to help them, may – justifiably – stifle acceptance of further genetic inquiry at a time when a major milestone in understanding genetics – the initial sequencing of the human genome – has just been reached.

This analysis is structured as follows:

Part I provides a cursory analysis of the relevant science relating to genetics and privacy.

Part II provides an overview of the legislative schemes in Canada dealing with privacy and discrimination generally. Part II also outlines specific initiatives aimed at genetics issues, both in Canada and in several other jurisdictions.

Part III explores a broad range of genetic privacy and discrimination issues.

Part IV contains recommendations for specific action to protect genetic privacy and prevent discrimination.

The range of genetic privacy and discrimination issues is enormous and growing. This brief paper can only touch on some of the major themes. It cannot fully address the vastly complex issues of genetics, privacy and discrimination – issues that for more than a decade have dominated much of

¹ “Employers Should Be Barred From Accessing Genetic Information, Americans Say In NCGR Survey,” March 4, 1998: <http://www.ncgr.org/about/news/archive.html>.

the ethical and legal debate surrounding genetics. For reasons of brevity, it does not deal in any detail with forensic applications of DNA in criminal investigations or the use of genetic information to enhance the targetting of biological weapons.

Part I: The Science

1. What Genetic Technology Can Reveal

Genetic technology is not new. Simple tests have been used for decades to identify chromosomal problems.² However, the relatively recent advent of “molecular genetics”, which enables the identification of genetic defects in the DNA molecule itself, has magnified the impact of genetic testing. As one author states, “the ability to identify genetic defects in the DNA molecule itself has led to a higher degree of specification of genetic disorders than has ever before been possible.”³ This enhanced degree of detail about behavioural and physical characteristics has intensified the privacy and discrimination issues relating to personal information generally.

The extent to which individual characteristics and behaviours are determined by genes is the focus of the debate surrounding “genetic determinism” – the belief that all human behaviour is governed by a chain of determinants that runs from the gene to the individual to the sum of the behaviours of all individuals.⁴

² J.T.R. Clarke, “Professional Norms in the Practice of Medical Genetics”, [1995] 3 Health Law Journal 130.

³ Clarke, above, at 138 .

⁴ Cited in Bartha Knoppers, *Human Dignity and Genetic Heritage*, a Study Paper prepared for the Law Reform Commission of Canada (Ottawa: Law Reform Commission of Canada, 1991) at 43.

Many claims about genetic links to diseases or behaviours are tentative. Some generate great controversy. Some researchers, for example, argue that genes appear to contribute to homosexuality; others dismiss this link.⁵ Amidst this still unresolved debate about the impact of genetics on characteristics and behaviours, “discoveries” about genetic links to diseases or behaviours occur with increasing frequency. Among the many genetic “discoveries” of the past few years, for example, have been a “salt gene” that could explain why some people with high blood pressure respond to a low-salt diet, and others do not; a finding that black smokers appear to absorb more nicotine than white smokers, which could explain why black smokers have more trouble quitting and run a higher risk of lung cancer; a report that people who are miserable and depressed may have been born with a genetic predisposition not to be happy; a discovery about several genetic defects that increase the tendency to put on weight; a report about a genetic mutation that can cause heart failure; a report that a “novelty-seeking” gene may influence sensation-seeking in adults; a finding that one gene plays a key role in inflammatory breast cancer, the most deadly form of the disease; a finding that even dark-skinned people who carry certain genetic variations are at increased risk for skin cancer; and the discovery that alteration of a specific gene appears to contribute to both the common late-onset form of Parkinson's disease, and the rarer, early-onset form of the disease.

2. Uses of Genetic Information

Genetic information can be useful in several situations, among them:

- to assist in predicting, diagnosing, treating and preventing health conditions;
- to assist in making reproductive choices and decisions relating to reproduction generally;
- to assess suitability for employment;
- to assess the genetic consequences of exposure to certain workplace or environmental materials or contaminants – for example, radiation;
- to assess eligibility for services such as insurance and credit;
- as an identification tool in criminal investigations;
- for medical research;
- to verify gender in sports competitions;
- to determine paternity; and
- to assess the susceptibility of ethnic groups to genetically-tuned biological weapons.

⁵ L. Hood and L. Rowen, “Genes, Genomes, and Society”, in Mark Rothstein, ed., *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era* (New Haven, Yale University Press, 1997) at 27; but see *The Independent*, May 3, 1998: “Despite claims that area Xq28 of the X chromosome contains a gene giving a “tendency” to homosexuality, scientists dismiss the idea.”

Most genetic diseases involve many genes and often also involve environmental components (that is, they are “multifactorial” diseases). Such diseases include hypertension, diabetes and coronary heart disease. Multifactorial diseases are highly difficult to predict through genetic testing simply because so many genes and environmental factors may be involved. Scientists may be able to say little more than that the presence of a particular gene or genes contributes to the risk of acquiring a disease, but they cannot state with certainty whether the individual will develop the disease. Contrast this with the relatively rare single gene (monogenic) diseases, where a mutation in a single gene can indicate a certainty of acquiring the disease.

Part II: Legislative Schemes Dealing with Genetic Privacy and Discrimination

3. The General Legal Framework

In many Western countries, there appears to be little legislation dealing *specifically* with genetic privacy and discrimination. However, the list of laws and proposed laws applying specifically to genetics is growing, particularly in the United States and primarily in three areas – insurance, employment and criminal forensics.

In Canada, apart from legislation dealing with the use of DNA in criminal investigations, most provisions relevant to genetic privacy and discrimination are not found in laws dealing specifically with genetics issues. Instead, they appear in more general legislation – constitutional law, laws governing professional confidentiality, data protection (privacy) and human rights laws among them. Many of these general laws were drafted without genetics in mind. Nonetheless, they provide a substantial, if incomplete, legal framework for handling personal genetic information.

1. Constitutional Law

Some protection of personal genetic information from misuse by government is found in the *Charter of Rights*. This protection occurs through the fundamental rights of freedom of association, conscience and religion; life, liberty and security of the person; freedom from unreasonable search and seizure; and the right to equality.⁶ The *Charter* is clearly an important vehicle for protecting genetic privacy and avoiding genetic discrimination at the hands of government.

These *Charter* rights, however, are not absolute and must be read in light of section 1 of the *Charter*, which can limit the rights stated elsewhere in the *Charter*. Even so, stringent conditions must be met before section 1 limits a constitutionally protected right.

2. Federal and Provincial Data Protection Laws

⁶ Knoppers, *above*, at 41-42.

Parliament and most provincial legislatures have now enacted data protection legislation that regulates the collection, use and disclosure of personal information by governments and many government agencies. Until recently, only Quebec had enacted data protection legislation regulating the private sector. As of January 2001 federal legislation, the *Personal Information Protection and Electronic Documents Protection Act*,⁷ will regulate the collection, use and disclosure of personal information by commercial organizations that are federally regulated. It also provides individuals with a right of access to information held about them. However, the Act exempts “personal health information” for one year after the legislation comes into force. The collection, use or disclosure of personal health information will not be covered until January 2002.⁸ Personal health information includes “information derived from the testing or examination of a body part or bodily substance of the individual,”⁹ and therefore includes genetic test results. Confusion remains about whether the Act covers physicians, since the Act applies to commercial organizations, and there is some doubt whether this includes the traditional professions.

If provincial governments fail to enact similar data protection legislation governing provincially regulated commercial activities within three years of the Act coming into force,¹⁰ the *Personal Information Protection and Electronic Documents Protection Act* will extend to all commercial activity, both federal and provincial.

Data protection legislation is clearly relevant in discussing genetic privacy. Genetic information about an individual is “personal information,” precisely the type of information that data protection legislation is intended to regulate. However, data protection legislation varies from jurisdiction to jurisdiction and is often not an effective guardian of genetic information. The federal *Privacy Act*,¹¹ for example, imposes only loose restrictions on the collection and disclosure of personal information by the federal government.

3. Provincial Health Information Legislation

⁷ S.C. 2000, c. 5.

⁸ Sections 30(1.1) and (2).

⁹ Section 2.

¹⁰ Section 30(2).

¹¹ R.S.C. 1985, c. P-21, sections 4 and 8.

Three provinces – Manitoba, Saskatchewan and Alberta¹² – have recently enacted legislation to deal specifically with privacy and confidentiality of health care information, and Ontario is considering such a move. These acts regulate the collection, use and disclosure of medical records, including genetic records. As well, provincial legislation regulating health care and health care institutions often contains provisions protecting the confidentiality of medical information by limiting its further disclosure;¹³ such provisions would apply to genetic information.

4. Human Rights Codes

Human rights codes generally prohibit discrimination in employment and access to services on the basis of disability, and case law has extended the protection to cases of perceived disability. In Ontario, the legislation makes it clear that protection extends to cases of perceived disability. Thus, the potential for genetic discrimination is significantly reduced by existing human rights codes and by the decisions interpreting those codes,¹⁴ including a recent Supreme Court of Canada decision.¹⁵ There, the Court emphasized that the right to protection against discrimination on the basis of disability covers discrimination based on *perceived* disability. Still, the extent to which *future* genetic disability is protected by human rights codes is not clear.

¹² Manitoba: *Personal Health Information Act* (1997); Saskatchewan: *Health Information Protection Act* (1999); Alberta: *Health Information Act* (1999).

¹³ For example, the *Nursing Homes Act*, R.S.O. 1990, c. N.7, section 6; *Homes for the Aged and Rest Homes Act*, R.S.O. 1990, c. H.13, section 6; *Long-Term Care Act, 1994*, S.O. 1994, c. 26, sections 3(1) and 32 (1); *Ontario Drug Benefit Act*, R.S.O. 1990, c. 0.10, section 13(6).

¹⁴ See generally the discussion in Trudo Lemmens and Poupak Bahamin, “Genetics in Life, Disability and Additional Health Insurance in Canada: A Comparative Legal and Ethical Analysis”, in Bartha Knoppers, ed., *Socio-Ethical Issues in Human Genetics* (Cowansville: Les Éditions Yvon Blais, Inc. 1998) 114 at 201-09.

¹⁵ *Quebec (Commission des droits de la personne et des droits de la jeunesse) v. Montréal (City)*; *Quebec (Commission des droits de la personne et des droits de la jeunesse) v. Boisbriand (City)* [2000] 1 S.C.R. 665.

There has been some action in the United States to protect employees against genetic discrimination. The American Civil Liberties Union reported in 1998 that 12 states had enacted laws that protect employees from genetic discrimination in the workplace and that a handful of other states had legislation pending at that time.¹⁶ A 1999 compilation of employment laws prepared by the US National Human Genome Research Institute showed that 25 states had to that time enacted provisions on using genetic information in employment.¹⁷ No federal legislation has been passed in the US relating to genetic discrimination in individual insurance coverage or to genetic discrimination in the workplace. However, several federal bills were introduced during the last decade, and on February 8, 2000, President Clinton signed an executive order prohibiting every federal department and agency from using genetic information in any hiring or promotion action.¹⁸

5. Insurance Law

Human rights legislation does not prevent discrimination in insurance. In fact, current insurance law promotes the use of medical information for underwriting.¹⁹ For example, model provincial insurance legislation, the *Uniform Insurance Act*, requires an applicant for insurance to disclose to the insurer “every fact within the person’s knowledge that is material to the insurance”²⁰ No exception is made for genetic information.

Contrast this with the United States. A 1998 Associated Press report states that 150 million Americans insured at work have legislative protection against some forms of genetic discrimination in insurance. The report states as well that 24 states restrict what insurers can do with genetic information.²¹ A 1999 compilation of US insurance laws prepared by the US National Human Genome Research Institute showed that 41 states had enacted provisions relating to genetic privacy in insurance matters.²²

¹⁶ “Genetic Discrimination in the Workplace Fact Sheet”, (1998)
<http://www.aclu.org/issues/worker/gdfactsheet.html> (April 5, 1999).

¹⁷ http://www.nhgri.nih.gov/Policy_and_public_affairs/Legislation/workplace.htm (accessed October 31, 2000).

¹⁸ <http://www.ornl.gov/hgmis/elsi/legislat.html> (accessed October 31, 2000).

¹⁹ Lemmens and Bahamin at 271.

²⁰ Lemmens and Bahamin at 190.

²¹ “Test Patients Fear Losing Insurance”, Associated Press, April 11, 1998 (New York).

²² http://www.nhgri.nih.gov/Policy_and_public_affairs/Legislation/insure.htm (accessed

In the United Kingdom, there appears to be no legal prohibition against genetic testing in insurance matters. In November 1998, the Department of Trade and Industry announced a voluntary agreement with insurance companies. Among the terms of the agreement: all genetic tests must be individually validated before they can be used by the insurance industry, and those who take genetic tests are to have the right to keep the results from life insurance companies.²³ This right would last only until insurance companies can show that a genetic test has a proven ability to predict a person's premature death.

In July 2000, the Association of British Insurers submitted an application to the Genetics and Insurance Committee (GAIC), set up by the UK Department of Health, for approval of two genetic tests for Huntington Disease. In October 2000, the GAIC, announced that the reliability and relevance of the genetic test was sufficient for insurance companies to use the result when assessing applications for life insurance.²⁴

6. Statutory Torts

Four provinces – British Columbia,²⁵ Saskatchewan,²⁶ Manitoba²⁷ and Newfoundland²⁸ – have enacted statutory privacy “torts.” These laws make it a civil wrong to violate the privacy of another person without justification. In Quebec, there is no statutory tort of violation of privacy. However, article 1053 of the Quebec *Civil Code* may provide similar protection.

7. Professional Codes

²³ *The Independent*, November 14, 1998.

²⁴ “Insurance in the genetic age,” *The Economist*, October 21, 2000.

²⁵ R.S.B.C. 1979, c. 336, section 1(1).

²⁶ *The Privacy Act*, R.S.S., c. P-24, section 2.

²⁷ *The Privacy Act*, C.C.S.M., P125.

²⁸ *The Privacy Act*, S.N. 1981, c. 6, section 3(1).

Provincial legislation governs the professional conduct of physicians and some other health care professionals. Often, however, the legislation does not explicitly set out a duty of confidentiality as part of its standards for professionals. This gap is sometimes closed by relying on the confidentiality provisions of codes of professional conduct.²⁹ One voluntary code, the Canadian Medical Association's *Health Information Privacy Code*,³⁰ sets out the minimum requirements to protect the privacy of patients and the security and confidentiality of their health information. The code covers the collection, use, and disclosure of personal health information and rights of access to the information.

8. Laws Protecting Against Physical Intrusion

The criminal law may prevent the forced taking of DNA samples on which to do genetic testing. The physical intrusions necessary to obtain saliva, blood or hair could amount to a criminal assault if they occurred without the consent of the person or without specific legislative authority³¹ to take the samples. This is so even if the physical intrusion itself is very minor. Obtaining DNA without consent could also constitute civil battery.

9. Possible Quasi-Constitutional Protection: the *Privacy Rights Charter* (Bill S-27)

Because Canadian constitutional law lacks an explicit constitutional right to privacy, the Hon. Sheila Finestone introduced a private senator's bill, Bill S-27, the *Privacy Rights Charter*, on June 15, 2000. The bill, intended to give privacy quasi-constitutional status, would guarantee the right of the individual to privacy. It would define what is an infringement and provide a test for justifiable infringement. It would also entitle individuals to claim and enforce their right to privacy, and to refuse to unjustifiably infringe the privacy rights of others. It would prohibit unjustifiably infringing the right to privacy of another individual.

The bill would also require the Minister of Justice to review bills and regulations for compliance, and entitles the Privacy Commissioner of Canada to be consulted in this regard.

²⁹ Gilbert Sharpe, *The Law and Medicine in Canada*, 2d ed. (Toronto: Butterworths, 1987) at 223-24. Though the text is already dated, the commentary appears to remain relevant

³⁰ Approved by the CMA Board of Directors, August 15, 1998.

³¹ Such as that provided by 1995 and 1998 amendments to the *Criminal Code* (and by parallel amendments to the *National Defence Act* that came into effect on June 30, 2000) to permit the police to take DNA samples from certain criminal suspects and from those convicted of certain criminal offences.

Unlike the *Charter of Rights*, which applies only to government, the *Privacy Rights Charter* would also apply to the federally-regulated private sector and could serve as a template for similar provincial legislation. (Only Quebec, with its *Charter of Human Rights and Freedoms* has already give a similar quasi-constitutional status to privacy, by affording every person the right to respect for his or her private life.)

Bill S-27 died when the federal election was called in October 2000, but will very likely be re-introduced after the election.

4. Examples of Canadian Laws and Other Initiatives Directed Specifically at Genetics Issues

1. *Bill C-47: Human Reproductive and Genetic Technologies Act*

Bill C-47, the *Human Reproductive and Genetic Technologies Act*,³² was introduced in the House of Commons in 1996. The Bill sought to prohibit the use of certain reproductive and genetic technologies (including cloning) in relation to human beings, as well as certain commercial arrangements relating to human reproduction. The bill would have prohibited performing any medical procedure to ensure or increase the probability that a zygote or embryo will be of a particular sex, except for reasons related to the health of the zygote or embryo.³³ As well, the bill would prohibit performing any diagnostic procedure to ascertain the sex of a zygote, embryo or fetus, except for reasons related to its health.³⁴

Bill C-47 died on the Order Paper. The Minister of Health then announced that he would introduce comprehensive legislation – a combination of prohibitions and a regulatory regime – before the end of 1999. When the federal election was called in October 2000, no such legislation had yet been introduced.

³² 2nd Sess., 35th Parl., 1996-97.

³³ Clause 4(1)(h).

³⁴ Clause 4(1)(i).

2. Research Ethics

The August 1998 Tri-Council Policy Statement,³⁵ *Ethical Conduct for Research Involving Humans*, contains several provisions relating to privacy and genetic research involving human subjects. The policy statement does not have the force of law, but it offers strong guidance on ethical issues relating to genetic privacy and discrimination. Among the issues covered by the guidelines are the potential loss of benefits and other harms flowing from the further use of genetic information, commercial uses of genetic information and the banking of DNA material.

3. Report of the Privacy Commissioner of Canada, *Genetic Testing and Privacy*

³⁵ Medical Research Council of Canada, Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humanities Research Council of Canada, *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (August 1998).
Genetics, Privacy and Discrimination October 31, 2000 Page 18

In 1992, the Privacy Commissioner of Canada issued *Genetic Testing and Privacy*.³⁶ The report examined genetic privacy issues relating to employment, access to services, human reproduction and criminal investigations, among other topics. The report spoke of the need to protect the privacy and confidentiality of personal genetic information, and made 22 recommendations for that purpose. Among other topics, these recommendations dealt with the right “not to know,” the need to restrict or prohibit collection of genetic information by governments, employers and service providers, and the use of DNA in criminal investigations.

4. The Canadian Genome Analysis and Technology Program (CGAT)

The Canadian Genome Analysis and Technology Program was established in 1992 as the Canadian arm of the International Human Genome Project. CGAT established an advisory committee on research into the medical, ethical, legal and social implications (“MELSI”) of genetics in 1993. The MELSI advisory committee sought to identify priority medical, ethical, legal and social issues in Canada. CGAT funded numerous studies into these issues. Among the issues addressed by the advisory committee were genetics and insurance, and comparative international approaches to genetics issues. This work, as a component of the larger CGAT, ended in April 1997.

5. House of Commons Standing Committee on Human Rights and the Status of Persons with Disabilities

The Standing Committee made several recommendations relating to genetic discrimination in its April 1997 report on privacy rights and new technologies, entitled *Privacy: Where Do We Draw the Line?* The Committee called for immediate action to deal with privacy violations and discrimination flowing from genetic testing. It called for a review of genetic testing policies and practices in several areas -- employment, health, insurance, and criminal justice.

5. International Initiatives

1. The Proposed *Genetic Privacy Act*

³⁶ (Ottawa: Minister of Supply and Services Canada, 1992).

In 1995, model legislation, the *Genetic Privacy Act*, was completed at the Health Law Department, Boston University School of Public Health.³⁷

The authors described the Act as “a proposal for federal [U.S.] legislation. The Act is based on the premise that genetic information is different from other types of personal information in ways that require special protection.” The model act would impose tight restrictions on the collection, use and disclosure of genetic information. As well, there would be special rules regarding the collection of DNA samples for genetic analysis for minors, incompetent persons, pregnant women, and embryos. Exceptions would be made for DNA samples collected and analyzed for identification for law enforcement purposes if authorized by state law, and for identifying dead bodies. Research on individually identifiable DNA samples would be prohibited unless the individual authorized the research use, and research on nonidentifiable samples would be permitted if not prohibited by the individual.³⁸

2. Council of Europe *Convention on Human Rights and Biomedicine* 1997

The 1997 European *Convention on Human Rights and Biomedicine*³⁹ was opened for signature by Council of Europe member states, and non-member states which participated in its development, including Canada. As of October 2000, the treaty had not received sufficient ratifications from Council of Europe member states for it to enter in force. As well, Canada had not yet signed or ratified the treaty.

The convention bans all forms of discrimination based on the grounds of a person’s genetic make-up and allows the carrying out of predictive genetic tests only for medical purposes. The Convention also sets out rules for medical research and recognizes a patient’s right “not to know.”

3. *Universal Declaration on the Human Genome and Human Rights* (UNESCO 1997)

³⁷ Source:

http://www.ornl.gov/TechResources/Human_Genome/resource/privacy/privacy1.html (April 2, 1999).

³⁸

http://www.ornl.gov/TechResources/Human_Genome/resource/privacy/privacy1.html#intro (April 2, 1999).

³⁹ ETS No. 164.

In 1997, the General Conference⁴⁰ of UNESCO adopted the *Universal Declaration on the Human Genome and Human Rights*. The Declaration contains several provisions aimed at preventing genetic discrimination – for example, the right of everyone to respect for their dignity and human rights regardless of their genetic characteristics. Furthermore, “[t]hat dignity makes it imperative not to reduce individuals to their genetic characteristics and to respect their uniqueness and diversity.” The Declaration also prohibits discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity. It also proposes strict rules for genetic research.

4. Other International Instruments

Even if not specifically directed at genetics issues, many international instruments have a bearing on genetic privacy and discrimination. These include declarations and conventions dealing with human rights generally, research guidelines and conventions dealing with matters such as biological weapons.

Declarations and conventions on human rights, for example, address privacy rights, equality rights, rights of association, freedom of religion, the right to adequate health care and the right to establish a family. International agreements or guidelines on research may also help prevent genetic discrimination. Prohibitions against the development and use of biological weapons are also directly relevant to genetic discrimination, particularly as evidence mounts that genetic characteristics are being studied as possible ways to help target biological weapons against specific ethnic groups.⁴¹

⁴⁰ 29th Session.

⁴¹ British Medical Association, *Biotechnology, Weapons and Humanity*, Harwood Academic Publishers, 1999.

Part III: The Issues

6. Overriding Issues

1. Tension Between the Potential Benefits and Harms of Genetic Technology

Genetic technology shows great potential for the prediction, diagnosis, treatment and prevention of disease. At present, many of these benefits remain potential, since science has only an incomplete understanding of the complexities of health, disease and genes.

Threats to privacy and the risk of discrimination, however, are not merely theoretical. The use and misuse of genetic information about individuals has already led to genetic discrimination, sometimes about overt genetic characteristics such as skin colour or gender, and other times about genetic traits discoverable only through testing – sickle cell anemia, for example. Genetic information will almost certainly continue to result in discrimination and other violations of human rights unless individuals retain control over such information.

2. Is Genetic Information an Exceptional Form of Personal Information?

Is genetic information somehow “exceptional,” requiring different, perhaps more cautious and protective treatment than other types of personal information? This issue has not been resolved.

Some genetic information, such as eye colour, is normally benign; other such information promises to reveal secrets that may profoundly affect the lives of individuals and their families. It may simply be that genetic information brings privacy and discrimination issues into sharper relief than do some other types of personal information. Thus, genetic information may add urgency and depth to issues that have long been present.

3. The Right Not to Know

Individuals are not normally obliged to investigate their health status. This right not to know can be viewed as an aspect of individual autonomy.

Respect for autonomy can be used to support the argument that individuals should not be forced to acquire genetic information about themselves. In many cases, such information might not harm the individual. In other cases, however, this knowledge could be catastrophic – such as learning, against one’s wishes, that one has the gene that causes Huntington disease.

The Privacy Commissioner of Canada has argued that everyone has a right to a reasonable

expectation of genetic privacy. This includes the right “not to know” about oneself.⁴²

Another aspect of this issue relates to minors. Should a minor have an equivalent right not to know? If a genetic test is looking for a condition for which no treatment is now available, or if a test is predictive of a disorder that will occur only in adulthood, the moral and ethical case for parents to seek genetic testing for a minor may be weak, even if the parents have the right in law to seek the testing. A recently reported technique to test every chromosome in a human embryo before it is implanted in the womb raises equally troubling issues. A news report about the technique states that it will make it possible to know the entire genetic makeup of a baby before it is born.⁴³ If so, the child could be born already saddled with a genetic “pedigree” that he or she may not later want to know as an adult.

4. Secret and Private Testing

An emerging factor in the debate over genetics, privacy and discrimination is the prospect of widely available private genetic tests.⁴⁴ As now occurs with home pregnancy test kits, individuals may one day be able to identify specific genetic characteristics by using a commercially available, and likely increasingly affordable, test. Similarly, they could use such tests to determine the genetic characteristics of anyone whose genetic material – saliva or hair roots, for example – is accessible to them.

The main impact of the tests lies in the likely expansion of situations where people will be tested, perhaps even without their knowledge. Easier commercial availability of testing kits will inevitably invite the surreptitious testing of others. Even if not used surreptitiously, the availability of these diagnostic tools to the general public may encourage their misuse.

The commercial availability of private genetic tests also has implications for the insurance industry. Those with a family history of a debilitating disease might use such a test to determine if they are at risk for the disease. If they are, they might then buy a large amount of life or disability insurance, but (fraudulently) without telling the insurance company of their increased risk. This “adverse selection” could impose an unfair burden on the insurance industry.

5. Disclosure to Biological Relatives

⁴² *Genetic Testing and Privacy*, above, at 30-31.

⁴³ “Genetic test opens door to quest for ‘perfect babies,’” *Ottawa Citizen*, October 23, 2000.

⁴⁴ See, for example, “Private gene testing should be allowed on trial basis -- bioethicist,” *Canadian Press* September 13, 1998, 23.03 EST (Edmonton).

There is considerable debate about whether a duty exists to share useful genetic information with biological relatives. Such information may safeguard the health or lives of those relatives. However, disclosing that information reveals the genetic traits of the family member who was tested, and that person may not want the test results disclosed to other family members. This poses serious ethical and legal dilemmas for healthcare workers who hold this information. Should they breach the obligation of confidentiality they owe their patient in order to protect the lives or health of biological relatives, or should the patient's right to confidentiality prevail?

6. Discrimination on the Basis of Perceived Disability

Case law has extended the protection against discrimination on the basis of disability to cover perceived disability, and the Ontario human rights legislation offers explicit protection against such discrimination. Thus, the potential for discrimination on the basis of both actual and perceived genetic disability is significantly reduced.

However, the extent to which human rights legislation and case law protect against discrimination due to the possibility of a *future* disability remains unclear. If an employer refuses to hire a person because the person has a genetic trait that may or will lead to disease, but the employer still considers the person to be healthy now, does that amount to discrimination on the basis of disability or perceived disability?

7. A Residual Right of Genetic Privacy?

Even if legislation, codes, ethical standards and other instruments were to provide adequate confidentiality protection, is there nonetheless a residual right to say "no" to uses of one's genetic information beyond the originally intended use?

This question is most germane in the context of research. Should a person with a severe genetic disability have the right to refuse researchers access to his or her genetic information, even if that research may be in the public interest? What if the goal of the research is to locate the gene that causes or contributes to the disability, so that in future it may be possible to "screen out" that disability from the population? Should a person have a right to refuse to participate in research if the ultimate goal of the research is to prevent the birth of others like that person?

Furthermore, even if there is no ethical issue such as that identified above, is there a residual right to be arbitrary – to deny someone else access to personal genetic information for no reason other than to assert one's right to control personal information about oneself?

7. Issues Relating to Specific Situations

1. Human Reproduction

Some of the most troubling privacy and discrimination issues relate to human reproduction. Cost-conscious governments will inevitably be drawn to programs that prevent the birth of children with genetic “disabilities.” Governmental pressure could take several forms:

- relatively neutral advice to prospective parents about the risk of giving birth to a genetically “defective” child;
- advice to parents not to have children, or to abort a “defective” fetus;
- positive financial incentives to abort or not to conceive;
- imposition of financial responsibility for the additional health care and other costs arising from the birth of a “defective” child; and
- compulsion not to have children, or compulsion to abort.⁴⁵

Subsidiary issues also arise, among them the following:

- how to prevent or restrict further dissemination (for example, to insurers, police, researchers, governments or employers) of genetic information acquired by private reproductive clinics; and
- rights, if any, of children conceived as a result of a sperm or egg donation to learn the identity, or at least the genetic background, of the donor, and the potentially conflicting rights of the donor to have information about him or her kept confidential.

2. Employment

Employers may think they have a clear interest in genetic information about employees or job applicants. The information of interest might include risk factors for early onset Alzheimer’s, heart disease, cancer, addiction, as well as some psychological traits and sensitivities to chemicals or other workplace contaminants. If the burden of health care costs shifts to the private sector, Canadian employers, like their American counterparts, may become much more interested in hiring only the healthiest employees with the “right” genetic stuff.

⁴⁵ The Privacy Commissioner of Canada, *Genetic Testing and Privacy*, above at 38.

As of 1990, there appeared to be little, if any, genetic testing of employees or job applicants in Canada.⁴⁶ This is likely still true, in part because human rights legislation offers some protection against the genetic discrimination that might flow from testing. However, the American Civil Liberties Union (ACLU) has claimed that U.S. employers have substantially increased their use of genetic testing in employment in recent years, and that in 1997, 6 to 10 per cent of employers conducted genetic testing. The ACLU also reported “many documented cases” of genetic discrimination. It cited a survey of nearly 1,000 individuals who were at risk for genetic conditions. More than 22 per cent reported some form of discrimination based on their risk status.⁴⁷ The U.S. Department of Labor and several other US departments found genetic information to be a workplace issue that warranted federal legislative protection “to ensure that knowledge gained from genetic research is fully utilized to improve the health of Americans and not to discriminate against workers.”⁴⁸

At issue is the extent to which employers should be able to obtain and use personal genetic information to make decisions about employing individuals and assigning them to certain tasks. And to what extent are current human rights provisions against discrimination adequate to deal with workplace genetic testing?

3. Testing to Determine Eligibility for Services Such as Insurance and Credit

Genetic information, like other medical information indicating health status, can impede access to services such as insurance and credit. Equally, such information might make people more easily and less expensively insurable, and might also facilitate access to credit. As a result, genetic information may further separate those who have access to insurance, credit and other services from those who, because of their genetic makeup, do not.

Furthermore, the fear that genetic information being sought for health care reasons could be used to discriminate in insurance and in the provision of other services may discourage some people from seeking medically useful – in some cases, possibly life-saving – genetic testing.

Genetic information may have an impact on access to other services as well. For example, individuals with “superior” genetic traits might be singled out for special educational or vocational

⁴⁶ The Privacy Commissioner of Canada, *Genetic Testing and Privacy*, above, at 16.

⁴⁷ American Civil Liberties Association, “Genetic Discrimination in the Workplace Fact Sheet”, ((2000) accessed October 23, 2000) [<http://www.aclu.org/issues/worker/gdfactsheet.html> (footnotes omitted)].

⁴⁸ Department of Labor, Department of Health and Human Services, Equal Employment Opportunity Commission, Department of Justice, *Genetic Information and the Workplace* (January 20, 1998).

training, while those with “inferior” traits might see themselves denied or restricted in their access to such opportunities.

Part IV: Recommendations and Conclusion

8. The Central Dilemma

At the heart of the debate over privacy, discrimination and genetic information is a concern that the failure to protect privacy and prevent discrimination will greatly diminish the potential for genetics to improve health and health care. Individuals may be afraid to undergo medically useful genetic testing or participate in socially useful genetic research for fear that this information may be used against them. Genetic inquiry may exacerbate loss of privacy and set the stage for greater discrimination. The most extreme uses of genetic information may go even beyond a deprivation of privacy and lead to genetically-based ethnic or racial “cleansing” or targeting of biological weapons.

Concerns about the misuse of genetic information are an extension of concerns about the misuse of personal information generally. Had society taken better care of non-genetic personal information to date, fears about the misuse of genetic information might be much less pronounced and much less justified.

9. Addressing the Issues

1. Education

Public education is essential to protect genetic privacy and prevent discrimination. Governments in particular have a duty to explain the uses of genetic information and their possible impact on society.

The 1992 report of the Privacy Commissioner of Canada, *Genetic Testing and Privacy*, is an example of the public education efforts that can help the public to grasp the significance of genetic privacy and discrimination issues. These in turn can lead to a more informed debate about the appropriate handling of genetic information. The work of the Canadian Genome Analysis and Technology Program and the 1999 *Final Report of the Advisory Council on Health Infostructure*, while not designed as vehicles for general public education, could also serve as useful starting points for the development of more easily understandable public education materials.

2. Control on Further Dissemination of Genetic Information

The key to benefitting from genetic information lies in controlling its uses beyond those relating to the health care of the individual to whom the information relates.

Particularly troubling, as seen with the US Department of Defense DNA collection program, is that DNA collected for one purpose (the identification of soldiers' remains) is also being made available for criminal investigations. Furthermore, in 1998, the FBI asked the U.S. government for extensive access to medical records without first getting patient permission, a request that would put numerous DNA databanks and patient records containing DNA profiles at the FBI's disposal.⁴⁹ A 1999 news report states that the Michigan Commission on Genetic Privacy has proposed that the state permanently keep DNA samples that had been taken for diagnosis of rare congenital diseases in newborns. The reason: the samples would prove valuable for law enforcement authorities and scientific research.⁵⁰ These developments will inevitably exert some influence on Canadian thinking about the handling of genetic information.

Calls for the extension of uses for genetic information that has been collected, and the seepage of practices and philosophies across our border, must be watched closely. It should not be the function of a DNA data bank assembled for health care or research to serve state authorities as a convenient object of plunder. Yet controls in Canada on such uses of DNA are weak.

Similarly, DNA collected and analyzed for health care purposes should not automatically be available for further uses, even research, if the DNA can be linked to an identifiable individual. The dissemination of this information to private commercial interests must also be tightly controlled.

⁴⁹ American Civil Liberties Union, *The Year in Civil Liberties 1998*. Web site: <http://www.aclu.org/library/ycl98.html> (April 5, 1999).

⁵⁰ "Michigan Wants to Expand DNA Databank of All Newborns", *The Detroit News*, January 26, 1999.

Some legislation already protects genetic information. The *Charter of Rights* protects against abuses by government and against legislative measures that violate the guarantees of the *Charter*, but the full extent of that protection for genetic information will remain unclear for some time.⁵¹ Legislation governing the private sector is inconsistent and incomplete. The recently enacted *Personal Information Protection and Electronic Documents Protection Act* will offer some protection against unwanted secondary uses of personal genetic information by commercial organizations, although the extent of those protections is not yet completely clear and will have to await judicial interpretation. As well, health information legislation such as that enacted recently in three provinces will help to promote “fair information practices” when dealing with genetic information. Statutory torts, codes of professional conduct, ethical guidelines and confidentiality provisions in health care legislation can also restrict the further uses of personal genetic information, although their effectiveness will vary.

Extensive legislative regulation and, in some cases, prohibitions, on secondary uses of personal information are indispensable for safeguarding the public interest and the privacy of individuals once information has been collected. The ultimate protection, however, may often lie in more carefully limiting the *initial* collection of personal genetic information.

3. Genetics-Specific or General Legislation?

Much of the discussion about protecting genetic information centres on whether specific genetic legislation is needed, or whether appropriately drafted general legislation will reduce discrimination and violations of genetic privacy.

Lemmens and Bahamin argue that regulating the use of genetic data, as a separate category of health-related information, could be impractical. “But it is important to point out the kinds of problems created. That might convince people of the need for stricter regulation of the use of medical information in general.”⁵²

Professor Mark Rothstein argues that “carefully crafted generic – rather than reflexively genetic – laws hold the greatest promise for protecting genetic secrets.”⁵³ Rothstein also concludes that there

⁵¹ An explicit constitutional right of privacy, a right strongly supported by the Privacy Commissioner of Canada, would offer some comfort that DNA in the hands of government institutions would not without strong justification be made available for new uses.

⁵² Lemmens and Bahamin, above, at 150.

⁵³ Mark Rothstein, “Genetic Secrets: A Policy Framework,” in Mark Rothstein, ed., *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era* (New Haven, Yale

is essentially no difference between ordinary medical information and genetic information, and that both types of information should be subject to the same protections.⁵⁴

Indeed, rules governing personal health information generally can equally protect genetic information. Thus, legislation, policies and ethical guidelines for health information generally are relevant to genetic information. However, as stated earlier in this report, genetic information brings new intensity to the need to protect personal health information because of the abundance of sometimes highly sensitive personal information that genetic science produces or promises. In some situations, legislative and other measures aimed at protecting health information generally may not deal appropriately with the peculiarities of genetic information. Among the issues that need to be addressed specifically because of the familial nature of genetic information are:

- whether and how to regulate the disclosure of genetic information about one person to that person's biological relatives where the information may be helpful to them; and
- whether it is possible and, if so, how to protect the right of biological relatives "not to know."

As well, legislative measures may be needed to protect the right "not to know" of minors, including measures to protect against newborns from being saddled with a genetics "report card" at birth.

Forensic DNA legislation is another area where specific rules are needed. Canada has developed legislation dealing with the taking of DNA from criminal suspects and the establishment of DNA databanks relating to convicted offenders. However, this legislation must be carefully monitored to prevent an unwarranted enlargement of its scope.

4. Other Measures

Human reproduction: International and constitutional law offer some protection against discrimination by the state in matters relating to human reproduction. In particular, the right of privacy, preferably explicit, in conjunction with other rights, such as freedom of association, might forestall governments seeking access to genetic information for the sake of interfering with decisions relating to human reproduction. How well these legal measures will protect reproductive rights, particularly as governments are attempting to reduce health-care costs, must be watched. However, the greatest protection against state interference will come from preventing personal

University Press, 1997) 451 at 459.

⁵⁴ Rothstein, above, at 458.

genetic information from falling into the hands of the state in the first place by enacting adequate restrictions on the state's collection of personal information.

Insurance: Genetic information highlights important concerns in insurance matters. As with other issues discussed in this report, it is not necessarily the genetic nature of the information, but rather the fact that the information can be used “against” the person, that demands attention. If individuals forego medically useful genetic testing because they fear losing their own or their family members’ access to insurance, the main goal of genetic science – improved health care – is seriously undermined.

The solution – both to ensure access to the important good of insurance and to minimize privacy intrusions – may lie in prohibiting insurance companies from requiring medical information, genetic or non-genetic, for insurance policies of less than a stated amount. This would ensure that no Canadian could be denied basic insurance because of a genetic or non-genetic condition. Such rules would insulate insurance companies from the economic damage caused by adverse selection. It would eliminate the current disincentive for individuals to seek medically useful genetic testing.

For large amounts of insurance, it would continue to be appropriate for insurance companies to have access to relevant information about an applicant. However, companies should be prohibited from disclosing the information outside the insurance context. For example, they should be prohibited from disclosing genetic information to employers or other commercial interests.

Generally: The following measures would provide additional protection against the misuse of genetic information:

- ratifying the *Council of Europe and Convention on Human Rights and Biomedicine*.⁵⁵ As Professor Knoppers has argued, the debate about resolving genetics issues must be international. The solution may in part also need to be international;
- enacting statutory privacy torts in those provinces and territories that do not yet have them;
- encouraging provinces that have not yet done so to enact specific privacy and confidentiality protections for health care information;
- developing more detailed professional codes of conduct to deal with specific genetics issues, such as disclosure of information to family members; and
- enacting specific statutory protection in human rights codes against possible future disability.

⁵⁵ ETS No. 164 (1997).

10. Conclusion

Privacy and discrimination form only two sets of a complex array of issues surrounding genetics. Inattention to or deliberate neglect of privacy and discrimination issues can turn genetics from among the most promising advances in science into a powerful weapon for undermining fundamental human rights. The rapid advance of genetic science leaves little time to give real meaning to genetic privacy and to protect against widespread genetic discrimination.