Genetic Information and the Law:

Issues in the Insurance and Employment Settings

A Report

4th Health Law Day
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The Programme

The program for Health Law Day 2005 – Genetic Information and the Law: Issues in the Insurance and Employment Settings included the following presentations and speakers:

1. Genetic Testing and Genetic Information: A Scientific Overview
   Sherryl Taylor, Department of Pathology and Molecular Medicine, Queen’s University

2. Genetic Testing in Insurance: Risk Rating or Discrimination?
   Yann Joly, Research Associate, Centre de Recherche en Droit Public, Université de Montreal; Frank Zinatelli, General Counsel, Canadian Life and Health Insurance Association; Teren Clarke, Executive Director, Canadian Paraplegic Association (Alberta)

   Paul A Schulte, National Institute for Occupational Safety and Health (US); Craig A. Flood, Partner, Koskie Minsky LLP, Toronto;

4. Privacy Issues: Data Protection Legislation – Cohesive or Disparate Protection?
   Patricia Kosseim, General Counsel, Office of the Privacy Commissioner of Canada

5. Human Rights Issues: Genetic Discrimination or Extended Protection?
   Trudo Lemmens, Faculty of Law, University of Toronto; Hart Schwartz, Director, Legal Services, Ontario Human Rights Commission

It should be noted, however, that transcripts were not used in the preparation of this paper. This paper is intended to capture the spirit of the presentations made at Health Law Day 2005 and also provide a comprehensive overview of the issues. The presentations and discussion below hopefully reflect the thoughtful presentations made as well current comments and literature on the subject.
Introduction

Genetic testing and genetic information might be used to prevent the onset of disease, to ensure early detection and treatment, and to make reproductive decisions.

They might also be used for non-medical purposes, to help with insurance and employment decision-making. Insurers might wish to use a genetic test result for underwriting, just as they now use other medical or family history data. Employers might wish to ensure that an individual does not have a genetic risk which might affect his ability to work or which might raise safety issues for individuals or their fellow workers. Applicants for insurance might wish to disclose their genetic status to pay cheaper premiums and prospective employees who are prone to disease might wish to seek out another company or position.

Although the technical aspects of genetic testing are developing quite rapidly, many reliable genetic tests are currently not available on the market. Accurate genetic prediction is difficult and varies with the disease and type of test available. Only relatively rare single gene disorders, like Huntington’s disease can be detected with a sensitivity of nearly 100% by means of a direct genetic test. The prediction of other diseases is more limited. Consider that the discovery of genetic tests for hereditary breast cancer – BRCA1 and BRCA2 genes – account for only 5% of all breast cancer. Even if mutations in these genes are found, the individual course of the disease is hard to predict, since only 45-80% of mutation carriers develop the disease.\(^1\) Ongoing research with the BRCA1 and BRCA2 tests has also shown how assessments of the predictive value of tests may often be much too high at the early stages of the development of the tests.

Despite the fact that genetic testing is currently couched in the language of probabilities and susceptibilities rather than certainties, testing holds the potential to assess the future risk of disease. In addition to the current limits in the technology of testing, understanding of what genetic information means is also imperfect. Just as “at-risk”, “predisposition” or “susceptibility” information is not the same as “certain” information, genetic information – even genetic mutation – is not synonymous with genetic disease.

\(^1\) Munich Re, Genetic Testing and Insurance – A Global View, 2nd Edition (Münchener Rück, Munich Re Group, 2004) at 2. [Munich Re].
It is not yet known how precise genetic testing will become. It is predicted that techniques will continue to become more reliable, accessible, and cost efficient over time. If genetic testing becomes as routine as other medical testing and can be proven to be both scientifically and actuarially valid, then the question is whether genetic testing should be restricted to testing for health purposes or whether it is permissible to use for other purposes, such as in the contexts of insurance and employment.

How genetic information is defined and protected and what distinctions, if any, can be made between genetic information and more general health information needs to be carefully considered, as do distinctions between the use of genetic information for medical and non-medical purposes. Being denied insurance or employment on the basis of one’s genetic traits could have serious consequences not only for individuals, but for families, and society at large.

One of the social consequences of genetic testing feared the most is genetic discrimination. Discrimination may take a number of forms. In employment it may be rejection for employment, or the offer of lesser employment; in insurance it may be loss of access to insurance or access only under extraordinary conditions and at much higher expense.

This is the unfortunate irony of genetic testing: that the promise of advances in genetics for improved health and health care may be compromised by the fear of discrimination. Genetic testing for purposes of improved health or reproductive decision-making may be avoided for fear that test results will be disclosed to insurers and employers. Rather than a major medical breakthrough that may in time be able to prevent, treat or even help cure some of the genetic diseases, genetic information may be viewed as a personal, familial and societal disadvantage.

In order to protect against genetic discrimination but ensure that meaningful information is not unduly restricted once it is available, it is important to think prospectively, to look at possible paradigms to promote protection against unfair discrimination, and to encourage and foster open debate in the area of genetic testing in insurance and employment. The Health Law Day 2005 on Genetic Information and the Law: Issues in the Insurance and Employment Settings has been assembled to this end.
Discussion and Commentary on the Presentations

1. Genetic Testing and Genetic Information: A Scientific Overview

Although for our purposes, it is the uses to which genetic testing is put rather than the technology itself that is important, it is essential to understand what genetic testing is and the current limits of the information that can be obtained from testing. As we shall see, genetic testing is difficult to define as it blurs with other medical testing that reveals genetic information. Genetic information is also difficult to tease out from medical information and currently suffers from limited predictive value. This raises important questions regarding the use of genetic testing in insurance and employment decision-making. While genetic testing may on the one hand be considered “scientific” testing, on the other, it may be invested with a confidence that is excessive given its currently limited significance and predictive value.

In the first session on the basics of genetics and genetic testing, Dr. Taylor outlined the importance of the human genome, provided information on the language used in genetics, and revealed the extent and limitations of genetic testing and the information obtained therefrom. She pointed out that the science of genetic testing is limited by our incomplete knowledge of genes and their functions. Although it may be easy to develop a diagnostic test once genes are located, determining the genetic factors responsible for most diseases is complex. This not only calls the value of the information into question, it also makes it difficult to match a genetic anomaly to a disease.

1.1 Genetics Primer

The Human Genome Project\(^2\) is a fifteen-year international collaboration charged with tracking every chemical base in each of the estimated 20,000 to 25,000 genes\(^3\) as well as the spaces between them. Scientists believe that having a detailed map of the entire set of human genes will revolutionize medical practice, biomedical research diagnostics and therapies for genetic disorders.\(^4\)

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\(^2\) See the website of the Human Genome Project for more information, online: Human Genome Project <http://www.ornl.gov/sci/techresources/Human_Genome/home.shtml>.

\(^3\) Ibid. Note that the number of genes is uncertain, and that certain estimates have reached as high as 70,000 genes.

The Human Genome Project is focusing on the creation of genome maps that depict the order in which genes, genetic markers, and other landmarks are found along the chromosomes. Knowledge of these characteristics is important for genetic testing, whereby a person’s DNA is examined for some anomaly that may indicate that a gene or chromosome is responsible for a disease or disorder.

The DNA irregularity can be large – a missing or added chromosome or piece of a chromosome – or small – as little as one extra, missing or altered chemical base. Genes can be too abundant, inactivated or lost. Sometimes, pieces of chromosomes become transposed so that a gene ends up in a location where it is permanently and inappropriately turned on or off.

### 1.2 Genetic Testing

#### 1.2.i Terminology

The term “genetic test” frequently describes the investigation of genetic material. There are different types that are generally regarded as genetic tests.

- **Cytogenetic/chromosome tests** detect abnormal chromosomal numbers or abnormal chromosomal structures for disorders such as Down’s syndrome and Klinefelter’s syndrome.
- **Molecular or DNA tests** directly analyse DNA or RNA using polymerase chain reaction technology to detect the presence of specific mutations or alterations in structure or expression of the gene, such as in Huntington’s disease and BRCA.
- **Biochemical tests** analyze biological products of particular genes (rather than the DNA or RNA directly) to detect missing or altered proteins or metabolites such as phenylketonuria (PKU) testing in newborn screening and testing for Alpha 1.5

The analyses of proteins that are encoded by genes might also be considered genetic testing. It is also possible to study RNA that occurs as a messenger from DNA to protein.6

It has also been suggested that examining family history may be a kind of genetic testing since it yields precise predictions only in very rare cases but frequently reveals information that may be a pointer to DNA or chromosome analysis.7

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7 Munich Re, *supra* note 1 at 3.
There is some dispute over what amounts to genetic testing. Although direct testing of genetic material, chromosomal structures, and biological products of genes are undisputedly included, it is less clear whether medical or non-genetic testing that reveals genetic information should also be included (particularly given attempts to distinguish medical and genetic information).

1.2.ii Purposes of Performing Genetic Testing

Testing may be used for reproductive, medical, or non-medical purposes. The most common form of reproductive genetic testing is carrier screening. These tests determine if couples carry a mutation for a disease and thus risk passing to their children a recessive allele for inherited disorders such as cystic fibrosis or sickle-cell anemia. Genetic tests are also widely available for the prenatal diagnosis, the course of the pregnancy being dependent on the genotype of the fetus. Prenatal genetic testing is frequently undertaken for conditions such as Down’s syndrome.

Medical testing typically involves clinical testing for mutations of the chemical bases in the gene itself, such as the tests for the breast cancer BRCA1 and BRCA2 genes. In clinical research programs, genetic tests are used to identify tell-tale DNA changes in cancer or pre-cancer cells. These tests are used in helping with early detection, diagnosis, prognosis and treatment. The most widespread type of medical genetic testing, however, is newborn screening, which detects inborn errors of metabolism by verifying the absence of a protein that the cell needs to function normally.

Non-medical testing is typically used for insurance or employment purposes. In the insurance context, insurers may wish to use genetic testing just like any other medical or family history data. In employment, employers may want to ensure that an employee does not have a genetic risk that might affect his ability to work or that might raise safety issues for himself or others. Applicants might want to undertake non-medical genetic testing if they have a family history of disease, either to disclose negative test results or, if treatment is available, to lower their risk in order to access insurance and employment opportunities otherwise unavailable – or cost prohibitive – to them. Of course, the

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9 Ibid. at 436.
10 Ibid. at 435.
11 Provided test results can be used, individuals might want to undertake non-medical testing provided there is something they can do with the information that insurer or employer will take into account. For example, information from the UK suggests that in the case of familial hypercholesterolaemia, a single-gene genetic disease that is effectively treated by statin drugs, insurance companies may insure individuals
social implications of undertaking genetic testing for non-clinical purposes (see discussion infra) remains.

1.2.iii Monogenic and Multifactorial Diseases

Genetic testing is available for monogenic and multifactorial diseases. Monogenic diseases (i.e. Huntington’s disease) are rare but highly penetrant genetic diseases caused by mutations in single genes. Presymptomatic/predictive testing can identify whether individuals have, will get, or are at risk for, a single-gene, late-onset disorder. Testing is highly predictive in that it can identify healthy individuals who have inherited a gene for late-onset disease and who will go on to develop the disease (if they live long enough), even before symptoms appear.

But presymptomatic testing has informative limits because it is unable to predict exact age of onset or severity of symptoms. Its importance in terms of risk information is also reduced because this information is already available through family histories. Although this is a serious problem for affected families in both the insurance and employment contexts, it is not a problem that is newly raised by genetic testing. The importance of testing is also limited somewhat by the fact that the number of individuals with single-gene late-onset disorders is quite small.12

Multifactorial (or complex) diseases, like cancer, coronary heart disease, stroke, and diabetes are frequent and almost always caused by the interaction of several genetic and non-genetic factors. Although these “common” diseases are triggered by a combination of multiple genes and by a range of environmental and lifestyle factors, the relationship between genetic information and disease is not as clear. With the exceptions of familial forms of breast cancer, colon cancer and Alzheimer’s disease, strong genetic factors are rare. While mutations associated with many of these diseases have been identified, the predictive value of such testing, for risk assessment purposes, is questionable. Little is currently known about the many weak genetic factors involved in this complex interplay, so suffering from this condition at standard rates, or only modestly elevated premiums, if there is evidence that they are complying with the risk-lowering treatment. See Alison Stewart, “The Vexed Question of Genetics and Insurance” (June, 2004) Cambridge Genetics Knowledge Park, online: Cambridge Network <http://www.cambridgenetwork.co.uk>.

testing is of little value. Moreover, meaningful mortality data for individuals with genetic predispositions to disease has yet to be developed.

Susceptibility testing may identify healthy individuals who have inherited a gene that may put them at increased risk of developing a multifactorial disease. They may, however, never actually go on to develop the disease. Any increased susceptibility that might be revealed by a genetic test would most likely be relatively small. The most, therefore, that susceptibility genetic testing can do is to demonstrate a propensity toward disease. It cannot adequately account for external factors that may be as important as inborn characteristics.

1.2.iv Drawbacks and Benefits - Preliminary Conclusions

Some genetic testing may identify those who will be affected by genetic disease with near certainty; others may only indicate an increased risk of developing disease. Genetic testing cannot, however, reveal who will go on to develop the disease, when they will get sick, or how severely their lives will be affected. The best that genetic testing can do is classify individuals into those who have a mutant gene and those who do not; but, a mutant gene is not equivalent to a genetic disease.

This makes the usefulness of genetic testing and its predictions about genetic disease complicated, particularly in the context of actuarial significance and risk classification. Yet some suggest that increasing knowledge and understanding of disease will enable insurers and employers to make distinctions between treatable and preventable conditions and fatal disease.

Some individuals may prefer not to know that they are at risk of being affected by a disease. Others may prefer to know and may consider genetic testing a benefit. Indeed, as Dr. Taylor suggested, there are benefits to testing since individuals who might otherwise have been ineligible for insurance based on family history may become eligible based on genetic testing; those susceptible to multifactorial diseases such as cancer may take steps to lower their risk by lifestyle

13 Public opinion polls suggest that most people that are at risk of suffering from Huntington’s disease do not want to know.
14 See Government of Canada, Public Opinion Research into Genetic Privacy Issues (Ottawa: Pollara Research and Earnscliffe Research and Communications, 2003) [Pollara Research], presented to the Biotechnology Assistant Deputy Minister Coordinating Committee (BACC) and the Canadian Biotechnology Strategy (CBS), the Genetic Information Privacy Secretariat Government of Canada and Finance Canada, which indicated in part, that most people believed there were more benefits than drawbacks in knowing about an individual’s genetic information. 88% of people surveyed thought that the benefits of allowing doctors to have access to their genetic information outweighed the drawbacks; 80% for medical researchers; 60% for pharmacists; 59% for nurses; 20% for governments; 16% for insurance companies; and only 12% for employers.
changes/monitoring. This information might then be taken into account by insurers to provide coverage at lower premiums or by employers in their decision making process.

Still, after two decades of genetic testing, its impact on risk assessment remains relatively low. For the moment, only a very limited number of predictive tests are sufficiently reliable to be of any real use to insurers and employers. Dr. Taylor notes that most information garnered from genetic testing is not actuarially useful. Moreover, use of such information by insurers and employers raises concern of unfair discrimination that could deter individuals from testing for clinical purposes and lead to social exclusion. Lifestyle, habits and family history may be less contentious and may be more reliable indicators of risk. The question is whether such information may be regarded as genetic information or not.

1.3 Genetic Information

Genetic information is often regarded as unique because of its (a) predictive nature, (b) individual and familial character; and (c) social, psychological, scientific, and economic implications. The question is whether it should be regarded as exceptional information because of its unique and special status or whether it should be included within the more general ambit of medical/health information. How genetic information is defined will not only impact upon the way the information is used but also upon the way in which it is protected.

Is genetic information different from other health information, including non-genetic test results that reveal genetic information such as family histories? Consider the case of Huntington’s disease, a highly penetrant single gene disorder. If family history reveals that a parent of an insurance applicant or employee has or had the disease, there is a 50% chance that the individual will suffer from the disease as well. The information is predictive, familial and individual, just like genetic test information. Predictive genetic information can be obtained from family history, traditional medical tests, or genetic tests. The tools may be different, but the information obtained is the same.

Recent Canadian public opinion research into genetic privacy matters conducted by Pollara Research and Earmcliffe Research and Communications in 2003 indicate that genetic information is generally viewed like other health information but more fundamentally personal, given the potential for discrimination on the basis of genetic characteristics. Fifty-eight percent of people polled believe

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15 Non-genetic testing includes by itself, or in combination with, blood tests, protein tests, medical imaging processes, familial inheritance, and traditional medical histories.
16 Supra note 14.
that genetic information should be more strictly regulated than general medical/health information and that, to this end, insurance companies and employers should not have access to genetic information.\textsuperscript{17}

Similarly, in the UK in 2000, there was public uproar when the Genetics and Insurance Committee approved the use of genetic test results for Huntington’s Disease as scientifically and actuarially sound.

These responses underscore not only confusion over what genetic information is, but also the strongly held perception that genetic information is somehow different from other forms of health information. It also illustrates public reluctance over the use of genetic testing. Specifically in the case of Huntington's, information may be readily available through family history. The point is that individuals with families having highly penetrant single gene disorders will likely experience no greater difficulties with the use of genetic testing than with the use of family histories alone.

Assuming that genetic information is, albeit not uniquely, predictive, individual and familial, the social implications of genetic testing may influence whether genetic information deserves exceptional protection. Genetic information may create a genetic underclass,\textsuperscript{18} promote geneticism,\textsuperscript{19} deter individuals from undertaking genetic tests for clinical purposes, prevent participation in research programmes for fear of discrimination, and infringe on the right of privacy and the right not to know.

The right of privacy may be put at risk if genetic test results are used in the insurance and employment contexts, since individuals may be deprived of their ability to control not only what others know, but also how much information they want to know about themselves. Privacy rights may be invaded when individuals feel compelled to undertake testing, not for clinical health reasons, but rather for financial, insurance or employment based reasons.

Genetic information may be narrowly or broadly defined. A strict definition will limit genetic information to information that is derived from genetic testing (DNA analysis). The draft Genetic Privacy Act takes this narrow position and defines genetic information as:

\textsuperscript{17} Ibid.

\textsuperscript{18} Kristine Barlow-Stewart & David Keays, “Genetic Discrimination in Australia” (2001) 8 J. Law Med. 25, who in describing the creation of a genetic underclass, refer to cascading discrimination from genetic testing. This is a group of people who already have the misfortune of inheriting genetic mutations then suffer discrimination at the hands of insurance companies, which then limits their opportunity and freedom. The cascading comes because as genetic characteristics are passed from one generation to the next, so too is the discrimination that accompanies it.

\textsuperscript{19} See Susan Wolf, “Beyond Genetic Discrimination: Toward the Broader Harm of Geneticism” (1995) 23 J.L. Med. & Ethics 344 where she notes that geneticism, like racism and sexism, gives rise to an entrenched system of disadvantaging some and advantaging others based on a mixture of accurate and inaccurate ideas about genetics.
any information about an identifiable individual that is derived from the presence, absence, alteration, or mutation of a gene or genes, or the presence or absence of a specific DNA marker or markers, and which has been obtained from an analysis of the individual’s DNA or from an analysis of the DNA of a person to whom the individual is related.20

Under a narrow definition, genetic information is different from medical information. By limiting genetic information to information obtained from DNA or DNA analysis, it excludes other information obtained from biochemical tests, family histories and so on. The distinction leads to a genetic-exceptional approach where genetic information is regarded as unique warranting special status. An exceptional approach that strictly defines genetic information may justify insurers’ and employers’ access to medical information but not to genetic information. The distinction presupposes that medical information can be distinguished from genetic information,21 that genetic information requires special protection, and that access to genetic information would deny access to insurance or employment in a way that medical information would not.

The curious result of not treating medical/health information and genetic information cohesively is that individuals suffering from (currently) non-genetically-linked diseases (e.g., breast cancer based on family history) will receive less protection than individuals suffering from the same disease with a genetic link (positive BRCA 1 genetic test results). 22

Under a broad definition, genetic information is included within the ambit of medical/health information. The Human Genetic Commission in the UK takes this approach and defines genetic information as

21 Distinctions between genetic information and health/medical information suggest a ‘two bucket theory of disease’ – one for health information and one for genetic information. See Murray, supra note 12 at 60-73., who notes that this is not easily adoptable since it requires us to categorize and toss every disease and risk factor into a genetic or non-genetic bucket – and many diseases do not neatly fit into one or either bucket.
22 See Trudo Lemmens, “Selective Justice, Genetic Discrimination and Insurance: Should We Single Our Genes in Our Laws?” (2000) 45 McGill L. J. 347; Margaret F. Otlowski in Implications of Genetic Testing for Australian Insurance Law and Practice, Occasional Paper No. 2  (Hobart: Centre for Law and Genetics, 2001) 52 at 53 writes “…it does seem contrary to our sense of fairness to offer special protection to a person who is affected by a ‘genetic’ risk but discriminate against a person who has a comparable ‘non-genetic’ form of the same disease.” Ironically, note that genetic-based breast cancer represents only a small portion of the population that suffers from breast cancer.
. . . any information about the genetic make up of an identifiable individual, derived directly from DNA or other biochemical testing methods or indirectly from any other source – including the details of a person’s family history.23

In a similar vein, UNESCO’s *International Declaration on Human Genetic Data* defines genetic information as “information about heritable characteristics of individuals obtained by analysis of nucleic acids or by other scientific data”24 (emphasis added).

This approach takes a more holistic approach to genetic information. The Australian Law Reform Commission (ALRC), for example, in *Essentially Yours*, believes it a mistake to deal with genetic information in isolation, since doing so would unfairly privilege genetic information as against all other forms of relevant health and medical information. They also consider that divorcing genetic information from medical/health information would create inconsistencies and thus remove it from policies, processes, and procedures already in place to ensure ethical oversight, best practice in clinical medicine, protection of privacy, and prohibition of unlawful discrimination.25

Assuming that it is difficult to distinguish disease information as either medical information or genetic information, medical/health information may need to be broadly framed. This would mean that medical/health information and genetic information are protected in the same way and that access to genetic information for purposes of risk classification is no different than access to any other medical information (actuarial and scientific validity issues aside).

### 2. Genetic Testing In Insurance: Risk Rating or Discrimination?

The insurance industry is likely to use the results of genetic testing as a component of the underwriting process in applications for personal insurance, where health information is defined as medical and genetic information and it is collected to assess the risk that applicants bring to the insurance pool.

Genetic testing may take the form of diagnostic, predictive or presymptomatic testing, particularly in relation to life insurance. Although the access to genetic information by insurers through medical

25 *ALRC 96 Report, supra* note 5.
information and family history is not new, there is some concern that as genetic testing becomes more prevalent, information relating to genetic disorders and disease susceptibility will become a more important component of the underwriter’s risk-rating process. The fear is that insurance companies will inappropriately use genetic information for risk assessment.\(^\text{26}\)

In this second session, Frank Zinatelli, Yann Joly and Teren Clarke considered genetic testing in the context of life, health and disability insurance coverage. It was suggested that genetic testing and information may need to be regarded in light of insurance as a social need without sacrificing the commercial interests and realities of the industry.

\section*{2.1 The Insurance Industry: Acceptable Discrimination?}

Life insurance is a private contract based on selection and risk-spreading according to the risk of death of either a primary or secondary income earner or both.\(^\text{27}\) It is a contract aimed at offering some form of financial security for unanticipated loss.

On the basis of risk assessment, applicants are entered into risk pools where others pay similar premiums based on similar risk profiles. Underwriting is the method used to classify people according to the relative risk. Information for underwriting comes from a variety of sources, including applicant questionnaires (that reveal age, sex, gender, lifestyle), data from medical files and the Medical Information Bureau’s databank, and family histories. Actuarial tables and statistics on morbidity and mortality are used to pool applicants according to risk status to set premiums.

It is thus the nature of insurance underwriting to classify applicants according to their (individual and familial) risk levels.\(^\text{28}\) It is this potentially discriminatory component that is at the centre of the debate over the use of genetic tests in insurance underwriting.\(^\text{29}\) The insurance industry maintains that if this type of risk assessment is discriminatory, then it is acceptable discrimination, since the nature of risk classification in insurance is based on differentiation. Genetic testing and information, in this regard, is simply an additional risk classification tool.\(^\text{30}\)

\begin{footnotesize}
\begin{enumerate}
\item[\textsuperscript{26}] Knoppers & Cardinal, \textit{supra} note 8 at 433.
\item[\textsuperscript{27}] \textit{Ibid.}.
\item[\textsuperscript{28}] \textit{Ibid.} at 453.
\item[\textsuperscript{30}] Trudo Lemmens & Poupak Bahamin, ‘Genetics in Life, Disability and Additional Health Insurance in Canada: A Comparative Legal and Ethical Analysis’ in Bartha Maria Knoppers, ed., \textit{Socio-Ethical Issues in Human Genetics} (Cowansville, Qc.: Yvon Blais, 1998) 115 at 157-160 [Lemmens & Bahamin].
\end{enumerate}
\end{footnotesize}
If medical/health information is broadly conceived and includes genetic information, it will likely be difficult to separate the information for underwriting purposes. Disclosure of, and access to, genetic information is based on the principle of mutuality of information in (especially life) insurance contracting and risks of anti-selection (see discussion, infra).

Provincial insurance legislation provides that an insurance contract is a contract of “utmost good faith based on full disclosure of risk.” 31 This requires applicants for insurance to disclose to the insurer “every fact within the person’s knowledge that is material to the insurance” or that a reasonable insurer would want to know before determining premiums. 32 No exception is made for genetic information since genetic information including family history, cholesterol levels, hypertension, heart disease, cancer, diabetes and many other conditions with a genetic component have been used in underwriting for years.33

As Mr. Zinatelli points out, the Canadian insurance industry’s position on genetic testing is unambiguous: for the risk classification and underwriting process to function correctly, it is essential that life, health and disability income insurers be able to access and use all relevant health information, including information from genetic tests. The Canadian Life and Health Insurance Association Industry Position Paper provides that “given the comprehensive basis of the underwriting process, genetic information is as integral to the process as family history.” 34

Currently, the insurance industry does not require that an applicant undergo genetic tests as a condition of issuing life or health policies. However, if genetic information from any earlier test is available to the applicant, the insurer may request access to that information with the applicant’s consent, just as it would for other aspects of the applicant’s health history. 35 Refusal to provide the information could mean that the application will be turned down.36

The industry is concerned that if genetic information is not accessible to them, as it becomes more sufficiently predictive of serious illness or death, applicants who know they are at high risk may be

31 See Ontario Insurance Act, R.S.O. 1990, c.I.18. See also similar legislation in other Canadian provinces.
32 Lemmens & Bahamin, supra note 30 at 271.
33 Canadian Life and Health Insurance Association Inc., Genetic Testing: Industry Position (Toronto: The Association, 2003) at 2 [CLHIA]. Compare this with the United States, where many states have legislative protection against some forms of genetic discrimination in insurance.
34 Ibid.
35 Ibid. The CLHIA position is that “…insurers would not require an applicant for insurance to undergo genetic testing. However, if genetic testing has been done and the information is available to the applicant for insurance and/or the applicant’s physician, the insurer would request access to that information just as it would for other aspects of the applicant’s health history.” See also Lemmens, Joly & Knoppers, supra note 29.
36 Ibid.
enticed to buy insurance or take out high value polices and make large claims based on undisclosed information.\textsuperscript{37} This is known as adverse selection or anti-selection. If it becomes widespread, it may “skew the bargaining relationship upon which the notion of insurance is based,”\textsuperscript{38} distort the insurance market, and unfairly affect other policy-holders.

The fear of adverse selection may be overstated since only a relatively small number of diseases are caused by single genes. Regardless, exploitation as a result of concealed knowledge largely depends on the size of the sum for which the life is insured. Since most diseases are caused by multiple genes in addition to the interaction of environment and lifestyle, the likelihood of skewing the relationship by deception is likely quite low. Further, as the therapeutic gap closes and treatment becomes available, the risk of being affected by a genetic disease will decline and adverse selection fears will abate as well.

The insurance industry’s code of ethics contains a commitment to confidentiality in the use of information, including genetic information.\textsuperscript{39} The industry also guarantees that genetic information will not be used in a risk assessment unless its validity and relevance have been clearly established either by scientific studies or some other means.\textsuperscript{40} Even so, arguments against access to genetic information include fears of discrimination, the resulting reluctance of individuals to undertake testing for clinical purposes, and the important role of life insurance.

\section*{2.2 Insurance as a Social Right?}

According to Mr. Zinatelli, 96\% of applications for insurance policies are approved in Canada.\textsuperscript{41} Of the remainder, half are approved with qualifications and the rest are rejected. Although genetic information currently represents a minor component in this decision-making process, it is clear that it could become more important as the science develops. Physicians specializing in genetic disorders suggest that many of their patients are among the 2\% of applicants rejected by insurance companies. Patients fear genetic discrimination and either refuse to undergo genetic testing or will not tell their children about their genetic predispositions.

This raises the issue of whether insurance should be a “societal right,” subject to laws and conventions governing equal access and discrimination. Mr. Zinatelli considered that insurance should be regarded

\textsuperscript{37} A study written in C.D. Zick \textit{et al.} “Genetic Testing, Adverse Selection and the Demand for Life Insurance” (2000) 93 Am. J. Med. Genet. 29 indicates that women testing positive for the BRCA1 mutation did not capitalize on the information by buying substantial amounts of insurance.

\textsuperscript{38} Knoppers & Cardinal, \textit{supra} note 8. See also Lemmens & Bahamin, \textit{supra} note 30.

\textsuperscript{39} CLHIA, \textit{supra} note 33.

\textsuperscript{40} \textit{Ibid.} at 1.

\textsuperscript{41} It is important to note that the number of applications does not correspond with the number of people who may actually wish to purchase health insurance.
as a spectrum of services, ranging from public insurance to private individual insurance. He also noted that while policy-makers recognize that some insurance, such as workers’ compensation, is a public right, they need to also recognize that the insurance industry is a business that must be allowed to make business choices.

The role of insurance in society is important. If insurance is only a commercial contract, then aside from issues of scientific and actuarial validity, genetic testing might be permissible, provided confidentiality rules are respected. But, if insurance has a larger social value, then it may be reasonable to regulate information that might be obtained from genetic testing.

The concept of insurance as a social good suggests that insurance should not be put beyond the reach of people who, through no fault of their own, carry genes that predispose them to illness. In other words, people should not be deterred by fears of discrimination from seeking information that may be important to their health. But if insurance moves from a voluntary, mutually-rated system based on equal information to one based on some sort of social good, such as social solidarity, then the concept of insurance will also need to change from a good that is a voluntary option to one that is essential and necessary.

One way to integrate both perspectives, as suggested by several commentators, is to have a two-tiered approach. On the first tier, basic contracts for insurance coverage below a certain ceiling amount would fall within a social solidarity framework, providing entitlement to a certain point without actuarial risk assessment. On the second tier, more “luxurious” high coverage contracts would fall within a mutuality framework based on equal information. Results from genetic testing would not be accessible on the first tier but would be on the second tier. Other approaches to insurance reforms have also been considered by the Canadian Genetics and Life Insurance Task Force (CGLITF).

### 2.3 The Canadian Genetics and Life Insurance Task Force (CGLITF)

Yann Joly, as a member of the Canadian Genetics and Life Insurance Task Force (CGLITF), points out the need to look at various approaches of reform put forward or followed by other countries in the area of genetics and life insurance to consider their relevance and applicability for Canada and further ongoing debate.

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The CGLITF, with members from academia, industry and consumer support groups, assembled to find a Canadian solution to the use of genetic information in insurance. The realities of the industry, the role of insurance in society, and the discontent that Canadians have currently voiced over the use of genetic information to determine the availability of insurance and the setting of premiums, were all taken into account.44

The Task Force notes concerns related to, inter-alia, the use and definition of genetic testing, the pressure to undergo testing for other than medical purposes, the fear of participating in genetic research and diagnostic testing, and the strongly held belief – albeit a misconception – that genetic information is something different than medical information.

The Task Force calls for an independent rigorous assessment of when new genetic information is sufficiently valid to be used by insurers with actuarial fairness. Actuarial sound classification is important, as are the social and medical repercussions of the use genetic information and public policy concerns of restricted access. The Task Force agreed on the need to debate the following two avenues:

- Encourage the Canadian Life and Health Insurance Association to acknowledge public anxiety by excluding genetic test results in risk-rating on a basic level of insurance coverage for a period of time to be determined by the association. The coverage and time limits could change as needed.

- Create an independent monitoring body made up of representatives from consumer groups, government, industry and the research community for ongoing review of criteria to determine the scientific validity of data for underwriting purposes.45

Yann Joly notes that ongoing debate of the Task Force’s discussion points has not yet been pursued nor have the Federal and provincial governments taken a position on the issue of genetic testing in insurance. Perhaps this is because Canada has still not had a reported/validated case of genetic discrimination in the area of insurance. Likewise, there has been no such case in the employment context. Still, the idea of stimulating debate should be encouraged so that core Canadian social values – such as access to insurance and employment – are not compromised now, nor in the future.

44 See Pollara Research, supra note 14 which found that the majority of Canadians reject the right of insurance companies to ask for genetic information – even if applicants have knowledge of a genetic condition.

3. Genetic Testing In Employment: A New Assessment Tool

As genetic testing increasingly becomes regarded as a tool to identify employees who may be at risk of disease due to workplace exposures, there are also growing concerns that genetic testing, particularly as it becomes less costly and more accessible, may be used to prohibit rather than promote employment. Interest in reducing costs related to occupational safety and work related diseases may entice employers to choose employees based on genetic traits rather than qualifications.

In this session, Dr. Paul Schulte and Craig Flood pointed out the limitations of genetic testing in the workplace and suggested that testing, if used, needs to be based on certain information rather than susceptibilities and relate only to job specific, non-discriminatory ends. Dr. Schulte considered the issue from an occupational epidemiologic perspective while Mr. Flood examined employer responsibilities and employee rights. They both discussed whether genetic testing can make workplaces safer by pinpointing genotypes and considered the extent to which employers are free to determine the means of selecting employees.

3.1 Genetics and Occupational Health: A New Epidemiologic Tool

According to Dr. Schulte, the use of genetic biomarkers in occupational epidemiological studies has the potential to be an important additional assessment tool. By identifying specific genotypes that are either sensitive or resistant to hazards in the workplace, genetic testing may contribute to the support of occupational safety and public health.

Dr. Schulte warns however, that it would be wrong to think that molecular and genetic measurement automatically result in better understanding of genetic disease and occupational risks. In terms of analytical validity, the concern is whether the genetic test is able to accurately and reliably measure the genotype of interest. In terms of clinical validity, the concern is whether the genetic test is able to detect or predict the associated disorder (phenotype). Although there is a strong lure toward the use of genetic technology, it may lead to narrow explorations that do not represent the most judicious use of scarce public resources.

As with the use of genetic information in general, privacy as well as the potential for discrimination against, and stigmatization of, certain workers or groups of workers are matters of concern. If, as suggested in earlier presentations, genetic information is protected in the same way as other medical

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46 See P. A. Schulte, “Some Implications of Genetic Biomarkers in Occupational Epidemiology and Practice” (2004) 30:1 Scand. J. Work Environ. Health 71 who notes that genetic testing can now be added to other epidemiological assessment tools that include questionnaires, job-exposure matrices, record review, and phenotypic data [Schulte].

47 Ibid.
information, rules relating to privacy protection, sensitivity of information and unfair discrimination will equally apply. Even so, the occupational setting provides a unique examination of issues related to interpretation, communication, and use of findings. Three examples are provided.

**Example 1: Disclosure of Uncertain Results**

**Study:** A small transitional genetic study was undertaken on exposure to ethylene oxide (EtO), (classified as a human carcinogen and used to sterilize hospital equipment and materials) by hospital workers. The study revealed that the absence of a certain gene may be related to a person’s risk of cancer if exposed to EtO. Participants were told of this “not certain” finding, despite its questionable statistical significance due to the size of the study group and the lack of epidemiological corroboration.

**Comment:** Epidemiologic information pertains to a group and not a particular individual. Assumptions about individual risks thus have to be made. Literature subsequent to the study suggested that participants not be told information that has no direct clinical relevance. However, clinical relevance in occupational studies is different from population based studies. In the occupational setting, clinical relevance may be defined as “whether participants could take reasonable preventive or medical action based on the results.”

**Example 2: Job-Related Testing**

**Study:** Studies reveal an 85-fold risk of chronic beryllium disease (a debilitating, sometimes life threatening fibrotic lung disease) for beryllium manufacturing plant workers with a human leukocyte antigen coding for glutamic acid in the 69th position (Glu 69). Importantly, (1) the predictive value of the screening test is poor; (2) there are other variants on the chromosome in question for which risks of chronic beryllium disease are suspected; (3) there is no curative treatment. Still, the employer, based on the studies, provides the information on Glu 69 to prospective employees. A voluntary and anonymous testing programme for employees is set up at a university and genetic counselling is provided. Prospective employees receive the individual results and the employer is only provided with the aggregate data.

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49 Ibid. at 73.

Comment: It is not clear that prospective employees should be screened for Glu 69 variant prior to employment. On the one hand, it may be best to provide genetic information to a person at risk to allow for individual decision-making. On the other, it may be a slippery slope to use in a mandatory pre-employment placement. For purposes of job placement, genetic information should be job related and consistent with business necessity. It is important to consider whether an employee’s ability to perform essential job functions will be impaired by a medical condition or whether the employee will be a direct threat to others due to a medical condition.

Although genetic exceptionalism arguments all have counter arguments that easily show medical information to have the same sensitivities and unique qualities as medical information, Schulte notes that genetic information and screening in the workplace is not necessarily a neutral technology. Rather, it is viewed in the context of power relations and involves important issues of control, use, and consequences of risk information.

Example 3: Premature Testing

Study: Railroad track workers filing injury reports or compensation claims for carpal tunnel syndrome due to repetitive stress in their work were tested, without their consent, for chromosome 17 deletion involving a protein, peripheral myelin protein-22 (PMP 22), which is not a test for carpal tunnel syndrome but rather for another disease that may manifest carpal tunnel syndrome. Studies show that on a population basis, such a deletion is rare.

Comment: Ethical and legal issues of absence of consent aside, this illustrates inappropriate and premature testing given both the lack of knowledge and inappropriate application of the test. Testing was not validated at the population level and little can be assessed in terms of predictive value or risk. Testing needs to be used with sufficient predictive value for clinical validity or fair risk assessment. Another important issue to consider in the workplace is whether immutable traits beyond a worker’s control should be factored into a claim of the work relatedness of a disease.

The new tool of genetic testing needs to be used appropriately. Currently, it is likely most useful in standard setting, risk assessment, and workers’ compensation claims. If and when genomic data can be interpreted in terms of population risks, appropriate protection for sensitive subgroups, either in terms of regulation or corporate risk management strategies, will need to be identified.

51 Murray, supra note 21.
52 Schulte, supra note 46 at 74.
3.2 Genetics and Employer-Employee Perspectives: The Attraction to Testing, Obligations, and Rights

Expanding on the attraction of genetic testing in employment settings, Craig Flood notes that employers’ attraction to genetic testing of employees is based on the assumed ability of genetic testing to predict future problems. However, as previously noted, most predictive genetic testing cannot determine whether an individual with a genetic predisposition will develop the disease in question, when its effects will appear, or how severe its symptoms will be. With testing of single gene disorders, only some tests are highly accurate while others are limited in their usefulness because of their low predictive value. Finally, testing for complex traits are also of limited reliability because they only indicate risk factors and cannot adequately account for interactions with environment, lifestyle and other non-genetic factors.

Genetic testing in the employment context in Canada is currently rare or non-existent. This may change, as noted, if genetic tests become less expensive and (despite the limitations noted above) are marketed as a tool to reduce human resource costs and maximize profits.53 Employers may seek to use genetic testing to screen or monitor employees or job applicants, reduce workers’ compensation claims, comply with occupational and safety obligations, determine suitability for a particular position, or increase productivity by screening out employees most likely to be absent from work due to illness.

Various provincial occupational health and safety acts and regulations currently provide regulatory structures under which health and safety standards are imposed on employers.54 For example, employers are required to create health and safety committees, allow inspection of worksites and provide employees with information about potential hazards and how to avoid them. Use of specific chemicals may also be regulated. With the growing attraction to genetic testing, there is some concern that such acts may be used to impose upon employers a duty of genetic screening and monitoring to provide a safe workplace. Further, employers might use this general duty to justify stringent screening and monitoring practices for workplace susceptibilities that could lead to discrimination based on speculative test results.

Genetic screening evaluates the pre-existence of genetic characteristics. This will typically be a one-time predictive or asymptomatic test that identifies whether an employee or job applicant, currently asymptomatic, has a gene that increases the likelihood that they will go on to develop a disorder as a result of the workplace environment. Screening may also be used to test for genes or disorders that

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54 See for example Ontario’s Occupational Health and Safety Act, R.S.O. 1990, c. 0.1.
are unrelated to the workplace but that render an employee (or prospective employee) undesirable to an employer. Genetic monitoring involves periodic testing of employees to identify potential effects of long-term exposure to workplace toxins. This may be regarded as useful to protect occupational health and safety, especially of employees with conditions are known to be affected by particular work environments.55

Before genetic testing is introduced into the workplace as a means of upholding health and safety standards, scientific evidence of harm will be needed and genetic testing will need to be able to establish a clear association between a genetic mutation and the development of a genetic disorder. If genetic testing is to become a workplace policy, it will need to support employment rather than allow exclusionary and discriminatory practices that prevent qualified employees (who might never develop a genetic disease) from obtaining a suitable job.

It is important to point out that employees may benefit from genetic testing in terms of making informed work environment choices. Employees may be interested in information that reveals susceptibilities to workplace hazards in order to request special accommodations or health and safety measures that would provide a healthier occupational environment. Not only would this ensure the safety of employees who are considered susceptible, but the health and safety of other employees as well.56

One of the concerns of workplace testing is that it may detract from overall workplace safety issues and place too much emphasis on individual risk factors.57 Consider the carpal tunnel case mentioned in example 3 above. The employer conducted genetic tests on all employees who filed a claim for carpal tunnel syndrome, without employee consent, to determine genetic predisposition. The

55 See U.S. Congress, Office of Technology Assessment, Genetic Monitoring and Screening in the Workplace, OTA-BA-455 (Washington, D.C.: US Government Printing Office, 1990) at 84-87 that provides examples of such genetic conditions, which include alpha 1antitrypsin deficiency, ataxia telangiectasia, and glucose-6-phosphate dehydrogenase deficiency.
56 See ALRC 96 Report, supra, note 5 who recommended that genetic information from an applicant or employee should not be collected or used for the protection of third party safety if the danger can be eliminated or significantly reduced by other reasonable means taken by the employer. Where this is not possible it is recommended that genetic information only be collected and used where the applicant’s or employee’s condition poses a real risk of serious danger to the health or safety of thirds parties and there is a scientifically reliable method of screening for the condition. Rec. 32-5. See also European Group on Ethics in Science and New Technologies, Opinion no. 18 Ethical Aspects of Genetic Testing in the Workplace (Brussels, July, 2003) at 15-16. Online: Europa Gateway to the European Union <http://europa.eu.int/comm/european_group_ethics/docs/avis18EN.pdf>
57 Lemmens, ‘What about your Genes?’ supra note 53 at 60.
employer argued that testing was done because the development of the condition could have “nothing to do with work.”

The fear is that responsibility for occupational health and safety would move from the employer to the individual employees whose genetic risk factors may be seen as the cause of occupational disease. Employers may refuse to hire employees who have an increased susceptibility to workplace hazards rather than improve environmental and health and safety standards. This would reduce the costs of accommodating at-risk employees as well as the number of workers’ compensation claims. As Bartha Maria Knoppers notes:

To ignore the complex nature of disorders and simply attribute the disease to poor genes would be an irresponsible error. Emphasizing the genetic aspect while underestimating the effects of workplace hazards, has the potential to shift blame or responsibility from the employer to the employee. Ironically, this shift of focus could even prove detrimental to “non-susceptible” employees. Companies might feel justified in relaxing health standards to the limits of the law if they feel confident that they have hired only “normal” employees.

If genetic testing with appropriate anti-discrimination and privacy safeguards and a system of regulation are put in place, it would likely introduce new responsibilities for employers. Where genetic information indicates that a worker may be predisposed to harm by working in a certain environment, employers may be required to transfer the worker to a different department. Employers would then need to deal with the departure of a meritocratic environment, possible disturbance of the seniority system, and criteria to determine which employees will receive preferred positions. Employers would also be responsible for providing a clean and safe working environment for all employees, rather than depriving some workers of their jobs in the name of occupational health and safety.

Since there is no Canadian jurisprudence on the subject, it is by no means certain that genetic testing in the workplace will be considered an acceptable labour practice in the future. However, a broad prohibition on the use of genetic testing and information would entirely ignore its potential uses for health and safety purposes. This would also, as previously noted, provide unfair protection to those

58 ALRC 96 Report, supra, note 5, ALRC, Issues Paper 26: Protection of Human Genetic Information, at 294, online: Australian Law Reform Commission <http://www.austlii.edu.au/au/other/alrc/publications/issues/26/>. The employer was the Burlington Northern and Santa Fe Railway Company. After a complaint was file to the US Equal Opportunity Employment Commission, the company agreed to abandon testing.
59 Knoppers & Cardinal, supra note 8 at 455.
60 See ALRC 96 Report, supra, note 5 at ¶ 30.51-30.52.
employees who have a genetic predisposition over those who have “other health risks.” As Lemmens suggests, rather than prohibition of genetic testing, regulation of access to testing may be required.\(^{61}\)

When and if genetic testing becomes more commonplace in the employment setting, controls over the improper use of genetic testing in employment will likely arise naturally from the activities of unions, which advocate on behalf of employee groups, and the judiciary, which recognizes that access to employment is an important Canadian value. As well, of course, privacy, anti-discrimination, occupational, and safety protections would also need to be in place.

Since genetic testing may be viewed as an extension of medical testing policies already conducted by employers, genetic information may be regarded as a component of an existing employment issue, which is access to medical records.\(^{62}\) Flood predicts that future genetic testing disputes will be heard before arbitrators, and not courts or human rights tribunals, as is currently the case in instances of misuse of confidential information from medical examinations and drug tests.

### 4. Privacy Issues: Data Protection Legislation – Cohesive or Disparate Protection?

Data protection legislation is clearly relevant to the discussion of genetic privacy and fears of discrimination. Data protection legislation is intended to regulate personal and personal health information. As we shall see, while genetic information tends to be read into the definition of personal information, it is rarely explicitly provided for. The legal framework of privacy and confidentiality of genetic information, including, *inter-alia*, PIPEDA and provincial and territorial legislation, does not extend unique privacy and confidentiality rules to the protection of genetic information.

In this session, Patricia Kosseim provided a broad description of protections offered under existing federal and provincial privacy legislation and outlined the proposed Pan-Canadian Health Information Privacy and Confidentiality Framework,\(^{63}\) which attempts to harmonize the protection of personal health information, including genetic information, across provincial and territorial jurisdictions. The goal, of course, is to create an effective (legislative) guardian of genetic information.

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62 Knoppers & Cardinal, *supra* note 8 at 455.
63 The ACIET reports to the Conference of Federal/Provincial/Territorial Deputy Ministers of Health and includes representation from Health Canada, all Provinces and Territories and the Canadian Institute on Health Information (CIHI), Statistics Canada, the National Aboriginal Health Organization (NAHO) and Canada Health Infoway among others. See online: Health Canada <http://www.hc-sc.gc.ca/hcs-sss/pubs/ehealth-esante/2005-pancanad-priv/index_e.html#intro>.
4.1 Federal Protection: Personal Information Protection and Electronic Documents Act (PIPEDA)

The relevant federal legislation that protects personal information, including health information, in the private sector is the Personal Information Protection and Electronic Documents Act (PIPEDA). Like other legislation, codes of ethics, standards, and procedures, PIPEDA requires health care professionals to protect patient privacy and support current best practices. It highlights the need of health care professionals to inform patients of the use, collection and disclosure of personal and personal health information and the need of organizations to collect, use, and disclose such information only in appropriate circumstances. Its purpose is to provide assurances to the public, patients and providers that personal health information will be managed and shared confidentially and securely.

PIPEDA sets out 10 principles that organizations – including health care providers in private practice, associations, partnerships, trade unions, agencies, institutions and individuals – must follow when collecting, using, and disclosing personal information in the course of a commercial activity (such as private pharmacies, laboratories or health care providers in private practices) and across borders.

Obtaining consent and identifying the purpose for the collection of personal information is a core feature of PIPEDA, as well as express consent, in some cases, for any secondary uses or disclosures of the information. The Act requires communication to individuals regarding what personal information is being collected, and how it will be used, disclosed and protected.

The Act distinguishes between personal health information and personal information, singling out health information from other types of personal information. Personal information is defined as “information about an identifiable person but does not include the name, title or business address or telephone number of an employee of an organization”. Personal health information with respect to an individual, whether living or deceased, means: “(a) information concerning the physical or mental health of the individual; (b) information concerning any health service provided to an individual; (c) information concerning the donation by the individual of any body part or any bodily substance of the individual or information derived from the testing or examination of a body part or bodily substance of the individual; (d) information that is collected in the course of providing health services to

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64 Personal Information Protection and Electronic Documents Act, S.C. 2000, c.5 [PIPEDA].
65 Taken from the National Standard of Canada’s “Model Code for the Protection of Personal Information”, the ten principles are: (1) accountability, (2) identifying purposes, (3) consent, (4) limiting collection, (5) limiting use, disclosure and retention, (6) accuracy, (7) safeguards, (8) openness, (9) individual access, and (10) challenging compliance.
66 See PIPEDA, supra note 64, s. 2(1) where organization is broadly defined.
individual; or (e) information that is collected incidentally to the provision of health services to the individual.”67 While *PIPEDA* does not use the term “genetic information”, the comprehensive definition of personal health information likely includes protection of an individual’s genetic information.

*PIPEDA* only covers personal information obtained in the course of commercial activity across provinces, or within provinces without “substantially similar” private sector privacy legislation in place. Quebec (November, 2003),68 Alberta (October, 2004),69 and BC (October, 2004)70 have been deemed substantially similar. Although *PIPEDA* will not apply to provincially-regulated organizations in these provinces, it will still apply to federal works, undertakings or businesses (FWUB) operating in these provinces. As noted, *PIPEDA* will also apply to inter-provincial and international transactions involving personal information in the course of commercial activities. *PIPEDA* will be the subject of a legislative review in 2006.

4.2 Provincial Protection: **The Ontario Personal Health Information Protection Act (PHIPA)**

In Ontario, an Exemption Order was published in the Canada Gazette on February 5th 2005, proposing to exempt from *PIPEDA*, Health Information Custodians (HICs) subject to the *Ontario Personal Health Information Protection Act, 2004 [PHIPA]*, in respect of the collection, use or disclosure of personal health information that takes place within the province. The *PIPEDA* will continue to apply to the collection, use or disclosure of all personal information outside the province, in the course of commercial activity. 71

*PHIPA* applies to HICs in the public and private sector. This is important because (1) personal health information is largely unregulated in the provincial private sector (since provincial and territorial statutes tend to govern the public sector within their jurisdictions); and (2) the majority of health information is privately held in the medical files of physicians.

*PHIPA* will soon test the principle established in *McInerney v. MacDonald* 72 that patients have a right of access to information in their medical records. Patricia Kosseim, the session presenter, referred to a case currently before arbitration in which a physician, acting as an independent examiner on behalf of

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67 Ibid.
68 See in Quebec *An Act respecting access to documents held by public bodies and the protection of personal information*, R.S.Q. c.A-2.1; *An Act respecting the protection of personal information in the private sector*, R.S.Q. c.P-39.1.
69 See *Personal Information Protection Act*, S.A. 2003, c. P-6.5. [*APIPA*].
70 See *Personal Information Protection Act*, S.B.C, 2003, c. 23 [*BCPIPA*].
an insurance company, provided the applicant and the company with a copy of his medical report but refused the applicant access to the notes that formed the basis of the report.

A review of other provincial health information protection legislation is pertinent, but beyond the confines of the current presentation. However, it is interesting to note that; (i) Quebec uniquely has two statutes – one that addresses access and protection of personal information in the public sector and another that addresses the same issues in the private sector; (ii) only the Northwest Territories and Nunavut do not specify that personal information must be recorded (possibly leaving the door open to perceived information?); and (iii) only Manitoba explicitly defines personal health information by using the term “genetic information” in addition to “inheritable characteristics”. It has been suggested that the harmonization of federal and provincial/territorial legislative regimes for the protection of personal health information may create a more consistent set of rules across all sectors.

### 4.3 Pan-Canadian Health Information Privacy and Confidentiality Framework

The proposed Pan-Canadian Health Information Privacy and Confidentiality Framework was developed by the Advisory Committee on Information and Emerging Technologies (ACIET) to create a harmonized set of core provisions for the collection, use, and disclosure of personal health information in both the publicly and privately funded health care sectors and to serve as a basis to review and revise, as necessary, existing legislation, or assist with enacting new legislation.\(^7\)

The framework defines and applies to recorded personal health information about an identifiable individual, sets the provisions for personal health information that is unrecorded, for anonymizing or de-identifying personal health information, and for personal health information that can be derived from the human body, including genetic information.\(^8\)

The framework proposes no separate or exceptional legislative vehicle to govern genetic information, which is viewed as a component of personal health information. This is assumed in the definition of personal health information that, *inter alia*, includes “information derived from the testing or examination of a body part or bodily substance.”

The ACIET argue that a harmonized and appropriate privacy and confidentiality regime for health information for provinces, territories and the federal government is needed to reflect the realities and

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\(^7\) *Supra* note 71.

\(^8\) The framework does not apply to health service provider information or to employee health records.
requirements of the health care system. They maintain that PIPEDA was drafted for regulating commerce and does not reflect the unique attributes and complexities of health care delivery. The proposal of this harmonized approach is expected to solidify the Provincial/Territorial rationale for amending PIPEDA through the statutory review process in 2006-2007.

Whether harmonization of privacy and confidentiality provisions will ease discrimination in the context of genetic testing in employment and insurance is not clear. Canadian Human Rights Law may offer some protection.

5. **Human Rights Issues: Genetic Discrimination or Extended Protection?**

One of the greatest worries arising from advances in genetic testing is that genetic information might be used to unfairly discriminate against people with “bad” genes, who have little control over their genetic make-up. Extended definitions of what accounts for disability and handicap and narrow bona fide justifications may provide protection from discrimination. But the issue of whether genetic traits should be intermingled with the notion of disability remains to be considered.

In the final session, Professor Lemmens traced the evolution of anti-discrimination case law in the context of insurance and employment, while Hart Schwartz pointed out that under the Ontario Human Rights Code, there is no basis for a human rights complaint on the grounds of disability if employees are asked to take a genetic test. Debate remains whether current protection from legislation and case law is sufficient or whether genetic specific protection is warranted. Again, such distinctions relate to how genetic information is defined.

5.1 **Prohibition of Discrimination**

In the context of genetic discrimination, case law has neatly set out two important issues that are useful to analyze and address when considering the extent to which human rights protection is

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75 There is a legal division of power in matters of health between the federal and provincial/territorial jurisdictions. The provinces and territories have general legislative jurisdiction over hospitals, the medical profession, the practice of medicine and general jurisdiction over health matters within a province/territory whilst the federal level has legal trade and commerce powers. The constitutionality of PIPEDA has been questioned as a possible encroachment on provincial powers.

76 The argument is to amend s. 4(2) of PIPEDA to exempt any organization in respect of personal health information that the organization collects, uses or discloses for health care purposes including health research and management of the health system.

77 Lemmens, Joly & Knoppers, *supra* note 29; Lemmens, “Genetics and Insurance Discrimination”, *supra* note 42.
available to those who suffer from, are perceived to suffer from, or who may in the future suffer from, discrimination on the basis of a genetic trait:

1. Is the genetic trait identified with a specific enumerated or analogous ground in existing human rights legislation?

2. What form of selection or exclusion can be justified as a *Bona Fide* Occupational Requirement?

### 5.1.i Protection Based on an Enumerated Ground

The *Canadian Charter of Rights and Freedoms*,\(^{78}\) the *Canadian Human Rights Act*\(^ {79}\) and human rights codes in all Canadian provinces\(^ {80}\) prevent or prohibit discrimination or discriminatory practices on specific enumerated grounds. Along with age, sex, and race, and so on, disability is an enumerated ground.

Human rights legislation now interprets disability to include *perceived disability*, although the perception of disability is not always explicitly included in the prohibited grounds of discrimination in provincial human rights statutes. In Ontario, s. 10(3) of the Ontario *Human Rights Code* provides:

> The right to equal treatment without discrimination because of disability includes the right to equal treatment without discrimination because a person has or has had a disability or *is believed to have or to have had a disability* (emphasis added).\(^ {81}\)

Nova Scotia has an equally expansive and explicit definition of disability.\(^ {82}\) However, even in other provinces where human rights legislation does not specifically mention perceived disability as a ground of discrimination, recent Canadian Supreme Court case law clarifies that the concept of disability includes *perceived disability*.

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\(^{80}\) See for example, the *Ontario Human Rights Code*, R.S.O., 1990, c.H-19, s. 1 which provides that “Every person has a right to equal treatment with respect to services, goods and facilities, without discrimination because of *inter alia*, race, colour, sex, age, marital status, family status, or disability.”.

\(^{81}\) *Ibid.* s. 10(3).

In *Boisbriand*,<sup>83</sup> a case involving three complaints from employees excluded from employment as a result of medical examinations that revealed asymptomatic conditions that did not impede with fulfilling their job-related duties, the court decided that asymptomatic conditions counted as a handicap, one of the enumerated grounds under the Charter. It noted that since the Charter does not define handicap, it should be interpreted in light of its context and objectives.

The court argued that the courts should adopt a multidimensional approach that considers the socio-political dimension of handicap. The emphasis is on human dignity, respect and the right to equality rather than merely on a biomedical condition. Courts will therefore have to consider not only an individual’s biomedical condition, but also circumstances in which a distinction is made. The court concluded that a handicap may exist even without proof of physical limitation or other ailments. The emphasis is on the effects of the distinction, exclusion or preference rather than on the precise cause or origin of the handicap.

This broad interpretation suggests that the notion of handicap and disability under human rights legislation will likely extend to both genetic predisposition (the likelihood of becoming disabled in the future) and perceived predisposition since handicap and disability may exist even without proof of physical limitations or ailments – precisely the situation of a person with a genetic susceptibility or predisposition that has not yet manifested itself, or may never manifest itself into a disability. Furthermore, while genetic predisposition and susceptibility rarely affect a person’s ability to do a specific job or obtain a service, it could be misinterpreted as an impediment. Extended interpretations mean that even if erroneously interpreted, a person with a predisposition or perceived predisposition will be protected under broad notions of disability/handicap.

The potential for genetic discrimination in insurance and employment thus seems significantly reduced by explicit wording in some human rights codes and by decisions that confirm the extension of the concept of (actual) disability to include perceived disability (even if not specifically mentioned in human rights law). Even so, some argue that the definition of disability should be expanded to explicitly include the predisposition to being disabled as a prohibited ground of discrimination in human rights legislation.<sup>84</sup> The reasoning is that, despite broad interpretations of disability, people who have a predisposition may never go on to develop the disease. Treating people who do not have symptoms of disability as though they do should be forbidden by law just as discrimination against

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<sup>83</sup> Quebec (Commission des droits de la personne et des droits de la jeunesse) v. Montreal (City); Quebec (Commission des droits de la personne et des droits de la jeunesse) v. Boisbriand (City) [2000] 1 SCC 665 [Boisbriand]. Two individuals had spinal anomalies and the third had asymptomatic Crohn’s disease.

disabled people is. The employer or service provider should be called upon to prove justification, the \textit{bona fide} occupational requirement for employment and the \textit{bona fide} justification for services.  

\textbf{5.1.ii Bona Fide Exceptions/Justifications:} 

Not all forms of differential treatment based on enumerated grounds are prohibited. There may be specific exceptions for discriminatory practices based on \textit{bona fide} justifications. For example, employers may exclude individuals from the workplace without infringing their right to equal treatment while insurers may discriminate on reasonable grounds according to accepted industry standards of risk assessment. However, \textit{bona fide} justifications have changed over time and moved from “sound and accepted business practices” as determined by the industry to a more refined test of “clear and substantial evidence.”

The Supreme Court of Canada first offered industry considerable leeway in \textit{Zurich Insurance Co. v. Ontario}, where it held that discriminatory criteria (i.e. such as sex and age to determine automobile insurance premiums) could be used as a fair business practice if “reasonable and \textit{bona fide} in the circumstances.” A discriminatory practice is reasonable if (1) it is based on a \textit{sound and accepted} (traditional) \textit{business practice} that is adopted to achieve a legitimate business practice (rather than to defeat rights protected under the Code); and (2) there is no other practical alternative. At the same time, the Court did however make it clear that the insurance industry should not continue indefinitely to use discriminatory criteria for rate setting by stating that “the industry must strive to avoid setting premiums based on enumerated grounds.”

Both McLachlin J. (as she then was) and L’Heureux Dubé J. strongly dissented. They maintained that while the discriminatory classification scheme was imposed in good faith, statistical correlations are not sufficient to justify the reasonableness of a discriminatory practice. The dissent also noted that a tradition of practice is not enough. The majority court’s application of the reasonableness test reveals its deference to the established tradition of the insurance industry. Other human rights complaints would certainly not be able to rely on tradition as an acceptable defence since otherwise attitudes and behaviours would likely never change.

The Supreme Court of Canada moved to a more contextual approach to examine discriminatory practice standards in both insurance and employment. In \textit{Law v. Canada (Minister of Employment}

\begin{itemize}
\item \textit{Ibid}.
\item \textit{Ibid}. Chap. 17.
\item \textit{Ibid}.
\end{itemize}
and Immigration), the Court adopted this approach, stating that the examination of discrimination is not confined to a fixed formula (even if based on an enumerated ground in the Charter). The issue before the Court was whether the law causes differential treatment and whether the differential treatment constitutes discrimination. A contextual approach to assessing discrimination examines the claimant’s perspective: Does the law draw a distinction between the claimant and others? Does the law fail to take advantage of the claimant’s already disadvantaged position? Is the claimant subject to differential treatment? The relevant point of view is that of the reasonable person in circumstances similar to the claimant who takes the contextual factors relevant to the claim into account.

The contextual approach was further developed in British Columbia (Public Service Employee Relations Commission) v. BCGSEU and confirmed again in British Columbia (Superintendent of Motor Vehicles) v. British Columbia (Council of Human Rights). Meiorin was a female firefighter who was dismissed for failing to meet the aerobic standard required for firefighters. There was no evidence to show the standard was necessary to perform the work of a firefighter. The SCC adopted a uniform three-step test for determining whether on a balance of probabilities, a prima facie discriminatory standard is a bona fide occupational requirement:

1. the standard must be for a purpose rationally connected to the performance of the job;
2. the standard must be adopted in honest good faith and belief that it was necessary to the fulfillment of the legitimate work related purpose
3. the employer must establish the standard is reasonably necessary to accomplish legitimate work related purpose.

To show that a standard is reasonably necessary, the employer must demonstrate that it is impossible to accommodate individual employees sharing the same characteristic as the claimant without imposing undue hardship upon the employer. If the tasks of the forest fire fighter can be safely and efficiently performed without meeting the aerobic standard, the rights of other fighters would not be affected. In her judgment, McLachlin C.J. wrote that “equality requires more than simply imposing a duty to accommodate those who are adversely affected without questioning the appropriateness of the standard.”

92 Meiorin, supra note 90.
The leeway given to industry under *Zurich* to determine if a discriminatory distinction is “*sound and accepted insurance practice*” and “*if there is no practical alternative,*” has given way to a stricter *bona fide* justification based on “*clear and substantial evidence*” and “*a duty of accommodation*” to look for reasonable alternatives to discriminatory practices under *Meiorin* and *Grismer*. As Professor Lemmens suggests, this new view of accommodation, coupled with a broader interpretation of what constitutes disability, may mean that genetic traits will be considered grounds for a discrimination complaint in the insurance and employment contexts.

The potential of genetic discrimination in insurance and employment does seem to at least be theoretically reduced by expansive human rights protections and recent SCC decisions. However, as Professor Lemmens and Hart Schwartz caution, the human rights complaints process is cumbersome and slow, limiting the potential protections offered by human rights legislation. Moreover, geneticism affects fewer people than racism or sexism giving it low priority on the human rights system. Finally, and importantly, human rights protection only provides posterior enforcement.

### 5.2 Options for Protection

The extensive interpretation of disability suggests that genetic discrimination may be sufficiently protected through the prohibited ground of disability and a broad understanding of human rights, fundamental freedoms, and human dignity. However, more certainty of protection against genetic discrimination may be provided by adapting existing human rights codes to explicitly include genetic susceptibility and predisposition as a prohibited ground of discrimination. The Ontario Law Reform Commission, for example, recommended that the Ontario Human Rights Commission issue an interpretative rule that genetic conditions are covered under existing human rights protections. It also recommended changing the existing definition of handicap to include prohibition of discrimination because “a person has or has had, or is believed to have or have had, or for the reason that it is believed that the person will have a disability.” The recommendation that perception of disability be protected from discrimination not only covers genetic susceptibility and predisposition, but also protects people against inappropriate use of health information by third parties such as

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93 See discussion generally in Lemmens & Bahamin, *supra* note 30 at 201-09.


96 *Ibid.*, Rec.18
insurers and employers.\textsuperscript{97} A recent report prepared for the Ontario Advisory Committee on Genetics reiterated this recommendation.\textsuperscript{98}

By including an anti-discrimination clause related to future health risks, Professor Lemmens suggests that the notion of disability may be entirely disconnected from genetic risk status thereby avoiding genetic determinism – the belief that carrying a specific genetic mutation has more impact on an individual’s well being than other health factors. This type of proposal avoids the pitfalls of a genetics specific approach since it concerns genetic discrimination in a general way within the context of health information and refers to broad social values.

There is reluctance to introduce specific protection against genetic discrimination in human rights legislation (or elsewhere). In addition to requiring another ground of discrimination to be added to existing legal documents, distinguishing genetic information from other grounds of disability would embrace a genetics specific/exceptional approach that would reinforce genetic determinism and contribute to, rather than alleviate, stigmatization and discrimination.

Prohibition of, access to, or use of genetic information is another means of protection. Restrictions may range from non-exclusive prohibitions to explicit prohibitions on the use of genetic information or genetic test results (even if the information is already in medical records). In the former instance, prohibitions suggest that “genetic testing may only be performed for health purposes or scientific purposes linked to health purposes.”\textsuperscript{99} In the latter case, broad and explicit prohibitions extend to both medical and genetic information. This may restrict information too much, especially where it prohibits the taking of family histories, (which is standard practice in the insurance industry), or prevents the insured from taking advantage of negative test results to lower premiums.\textsuperscript{100}

Countries like Austria\textsuperscript{101} and Belgium\textsuperscript{102} (among others) have tried to prohibit insurers from asking questions related to genetic test results or other genetic information. Legislation defines genetic test

\textsuperscript{97} The Ontario Advisory Committee on Genetics has reiterated this position.
\textsuperscript{98} Lemmens, Lacroix & Mykitiuk, supra note 12.
\textsuperscript{99} See Council of Europe, Convention on Human Rights and Biomedicine Arts 11 &12, available online: Council of Europe \texttt{<http://conventions.coe.int/treaty/en/treaties/html/164.htm>}; France, the Law on respect of the human body 1994, which state that a genetic study on an individual’s characteristics can only be carried out for medical or research purposes.
\textsuperscript{100} See for example France (Law No 2002-303 of March 4, 2002, relating to the sights of patients and the quality of the system of health (1) art 98) where insurance companies are prohibited from collecting, requesting, or accepting the results of genetic testing.
\textsuperscript{101} The Gene Technology Act of 1994.
results narrowly, as DNA analysis, thereby excluding family history. Since the door is still open for insurers to ask risk-related questions about an applicant’s family history, it is not clear what sort of protection is actually offered, given that family history may be used to assess the risk of a genetic condition, but information from DNA analysis may not be.

This approach seems only to reinforce genetic exceptionalism since it suggests that genetic information is different from other medical information. It also insinuates that genetic information can be clearly defined and easily distinguished from non-genetic information. This is less than obvious. If genetic information and medical health information are considered inherently intermingled and genetic information is a component of medical information often detected through medical/diagnostic tests, then prohibiting genetic information without similarly prohibiting medical information provides questionable protection.

A wait-and-see approach, or moratorium on any measures related to the prohibition of access to, or use of, genetic information, is also a temporary form of protection. Yann Joly, as a representative of the CGLITF, supported a moratorium on genetic testing in the context of insurance and employment because so much is still unknown about genetic information and its application.

The majority of moratoria are for a limited time, to allow debate over the use of genetic tests to continue and to continually evaluate the actuarial relevance of tests as technology develops and tests become cheaper. Some moratoria involve an absolute ban on the use of any genetic test results. Others, as in Canada, are more limited and represent a commitment on the part of industry not to introduce genetic tests as a pre-condition for insurance but still permit use of genetic tests known to the applicant.

Such an approach suggests that human rights and privacy laws are currently sufficient to safeguard against unwarranted discrimination and that additional protections, if needed, will take place alongside technological developments. Especially where insurers retain the right to ask for existing results, it is unclear whether this approach adequately takes account of public perception or provides reassurance

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102 See Belgium law, Article 95 of the Law on Insurance Contracts, 1992 which provides for a total ban on the use of genetic testing to predict the future health status of applicants for life insurance on the part of both the insured and the insurer.

103 Gene analysis under Austria’s Act supra note 101 is defined as comprising molecular biological investigations of human chromosomes, gene or DNA segments for the identification of disease causing mutations.

104 A moratorium is a non-binding strategy (though moral persuasion is typically sufficient to ensure that it is respected by professional associations) that is either indefinite (Germany), limited to a certain number of years (France, Switzerland), or limited to policies that surpass a certain value (UK, Sweden).
for those who want to undergo genetic testing for clinical purposes or participate in genetic research. Perhaps the greatest difficulty of the wait-and-see approach is that the debate surrounding the use of genetic information is put on the “back burner.” Protection is best provided if the debate remains in the foreground.

Human rights procedures have administrative and procedural limitations that may affect how well they respond to claims of genetic discrimination. It seems that the OHRC is not currently the best place to seek relief against genetic discrimination. Claimants must go through up to four “decision loops” (internal administrative decisions by OHRC officials) before being heard, and being heard may itself take a very long time due to the delay inherent in a popular system. Moreover, claims of genetic discrimination may not be suitable for isolated, individual claims, and may be better pursued in court through class proceedings (in Ontario under the Class Proceedings Act). Further, if the alleged perpetrator of discrimination is a government employer or agency, the Charter also provides for judicial remedies.

However, there are some other less conventional mechanisms within the Ontario Human Rights Code itself. For example, this legislation gives the Commission powers to strike inquiries “into incidents of . . . tension or conflict based upon identification by a prohibited ground of discrimination and take appropriate action to eliminate the source of tension or conflict.” Also, the Commission reserves an independent right to investigate a complaint that it has instantiated. An administrative reality remains that the OHRC must prioritize its complaints, and insurance-related complaints do not always merit top priority. If enough complaints related to a specific kind of discrimination emerge, the Commission may decide to embark on an inquiry of its own. Finally, the Commission has a periodic duty to file a report to the Legislature on overall compliance with the Code, and recommendations for reform. Already, the OHRC has addressed some genetic discrimination issues in its report, Human Rights in Insurance.

As a proposal for ongoing debate and as an alternative to a human rights approach to protection against genetic discrimination, Hart Schwartz suggested the option of a regulatory system that follows human rights cases related to genetic testing. A committee/commission could, independent of

105 Concerns should be abated somewhat since research findings are often not returned to participants, and if they are, it is because of clinical significance.
106 Ontario Human Rights Code, supra note 80.
107 Ibid., s. 29(f).
108 Ibid., s. 33(2).
industry, develop policy relating to the reasonable use of the technology and information, address matters such as the appropriateness of access to and use of genetic testing, and assess the scientific and actuarial validity of genetic tests. The Australian Law Reform Commission’s recommendation of the creation of the Human Genetics Commission of Australia\textsuperscript{110}, the UK’s Human Genetics Commission\textsuperscript{111} and a similar call from the Ontario Advisory Committee on New Predictive Genetic Technologies\textsuperscript{112} offer the best examples of this option. The importance of validating scientific information before implementing genetic testing policies including legislation is a key point for Professor Lemmens, who argues that validation will not increase research costs as changes to law and policy can only be implemented after research is conducted.

**Conclusion**

The impact of genetic testing in insurance and employment settings is still relatively low in Canada and elsewhere in the world given current approaches such as moratoriums, prohibitions, and outright (legislative) bans. In contrast, public awareness of genetic testing and understanding of the potential use of genetic tests results in these sectors is steadily rising. Concerns of genetic discrimination are for the moment outpacing use of the technology, but this situation is likely to change in the not-too-distant future when genetic testing for more common diseases becomes available and future risk can be more readily assessed. During this current gap between refinement and more commonplace use, there is a window of opportunity to discuss how to best reduce the fear caused by potential misuse of genetic tests by third parties.

Genetic testing is increasingly becoming an indispensable part of the standard armoury of clinical medicine. This makes it difficult to differentiate genetic information from conventional health information. Pharmacogenetics and preventive medicine are only two of the potential fields where genetic testing is expected to have a crucial influence, suggesting that the blur may even intensify.

\textsuperscript{110} *ALRC 96 Report, supra* note 5 ¶27.37, Rec. 27-1 et seq.
The link between genetic and medical information makes it tricky to develop a clear definition of what genetic information means and to determine what information protection should extend to. The need for demonstrable evidence of scientific validity aside, the process by which genetic information is incorporated into insurance and employment decision-making needs to be made transparent to ensure it is not being used to the detriment of individuals, or their families or communities.

Given that decision-making in these settings may in the future involve genetic testing, strategies need to ensure that a genetic underclass is not created, that appropriate health and clinical care are not negatively affected by fear of discrimination in insurance and employment, and that the right of privacy is not infringed upon. Continued discussion on the use, regulation, and protection of genetic information in Canada and other countries will help inform our debate and help find the necessary fine balance between insurers and applicants and employers and employees.