



Office of the  
Privacy Commissioner  
of Canada

Genetic Information,  
the Life and Health  
Insurance Industry  
and the Protection of  
Personal  
Information:  
Framing the Debate

*December 2012*

*This document is intended to provide the context and help readers understand two papers commissioned by the Office of the Privacy Commissioner of Canada on this subject.*

- [The Potential Economic Impact of a Ban on the Use of Genetic Information for Life and Health Insurance](#)
- [The Actuarial Relevance of Genetic Information in the Life and Health Insurance Context](#)

## Introduction

Advances in medical science together with ever more powerful and sophisticated computing technology have significantly lowered the cost and increased the availability of genetic testing.

Genetic tests can be used to confirm or rule out a suspected genetic condition; help determine a person's chance of developing or passing on a genetic disorder to their children,<sup>i</sup> allow individuals to take steps to mitigate the potential impact of a genetic condition; or personalize treatment to the needs of a particular patient.

As genetic testing has become more accurate and more widely used, interest in the use of genetic information for purposes other than health care or medical research has increased, for example, for employment or insurance purposes.

This has created concerns about the use of genetic information to make employment decisions, to charge higher insurance premiums, or deny coverage. This, in turn, has prompted fears that individuals may be forgoing genetic testing, and the health benefits these tests can provide, because of the possibility that their test results will be used in ways that will adversely affect them or their family members.

## The Response to Concerns about the Potential Uses of Genetic Information

Different jurisdictions have responded to these concerns in different ways. In the United States, the federal government adopted the *Genetic Information Nondiscrimination Act (GINA)* in 2008. In broad terms, GINA prohibits employers from using genetic information for hiring or compensation purposes and insurance companies from using genetic information to make underwriting decisions with respect to health insurance. Most American states have similar laws. California's law also prohibits genetic discrimination in areas such as housing, mortgage lending, education, and public accommodation.

Several European countries have prohibited, or introduced moratoria on, the use of genetic information by insurance companies. In the United Kingdom, the Association of British Insurers and the Government have agreed on a voluntary moratorium, recently extended to 2017, on the use of predictive genetic test results for life insurance policies under £500,000 or critical illness policies under £300,000. Above these amounts, insurers can only use tests results if the test, the disease and the product have been approved. At present, insurers are only allowed to use test results for Huntington's disease when selling life insurance. In Germany, insurers may only request genetic test results for life insurance policies that pay out more than €300,000 or for disability policies that pay more than €30,000 annually. However, the issue is far from settled in Europe.

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<sup>i</sup> The genetic contribution to disease is complex. See the glossary below. In some cases the presence of a genetic mutation in a single gene can accurately predict the likelihood that an individual will develop a particular disease. With multifactorial disorders multiple genes may be involved in combination with other factors that may be more relevant than the genetic mutations. As well, one's genetic make-up may make one less likely than average to develop a certain condition.

The Council of Europe issued a “Consultation Document on Predictivity, Genetic Testing and Insurance” in 2012.<sup>ii</sup>

## The Canadian Situation

Although the issue has been extensively examined at conferences,<sup>iii</sup> by academics and by a multi-stakeholder Task Force on Insurance and Genetics (2004), there are no laws in Canada that specifically address the use of genetic information by insurance companies. Nor has any government imposed a moratorium on the use of genetic information for insurance purposes. The *Canadian Human Rights Act* and provincial human rights codes are potentially relevant to the extent that they prohibit discrimination or discriminatory practices on the basis of disability, age, sex, race and other enumerated grounds.

The Canadian Life and Health Insurance Association (CLHIA) has issued a Position Statement on the use of genetic information stating that an insurer 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.”<sup>iv</sup> The CLHIA position is based on the general principle that an insurer needs to have all available material information about the applicant’s risk in order to properly assess that risk. From an insurance perspective, predictive test results are potentially useful in helping insurers assess the probability that an individual will develop a genetic disorder before any symptoms appear.<sup>v</sup>

## Privacy Legislation

The federal *Personal Information Protection and Electronic Documents Act* (PIPEDA) and the substantially similar provincial laws in British Columbia, Alberta and Quebec govern the collection, use and disclosure of personal information, including health and genetic information about identifiable individuals.

In terms of assessing the appropriateness of collecting and using genetic information, there are three principles in PIPEDA that are particularly relevant. The Consent Principle in Schedule 1 states that an organization shall not, as a condition of supplying a product or service, “require an individual to consent to the collection, use, or disclosure of personal information beyond that required for an explicitly specified and legitimate purpose.” The Limiting Collection Principle limits collection to that which is necessary for the purposes identified by the organization. The “reasonable person” provision limits the collection, use or disclosure of personal information to “purposes that a reasonable person would consider are appropriate in the circumstances.”

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<sup>ii</sup> <http://www.coe.int/t/dg3/healthbioethic/Source/Final%20E%20consult%20doc.pdf>

<sup>iii</sup> See for example a Policy Brief based on a workshop organized by Genome Canada, <http://www.genomecanada.ca/medias/pdf/en/GPS-Policy-Directions-Brief-2-EN.pdf>

<sup>iv</sup> [http://www.clhia.ca/domino/html/clhia/clhia\\_lp4w\\_ind\\_webstation.nsf/resources/Guidelines/\\$file/Genetic\\_Testing\\_CLHIA\\_Industry\\_Position\\_2010.pdf](http://www.clhia.ca/domino/html/clhia/clhia_lp4w_ind_webstation.nsf/resources/Guidelines/$file/Genetic_Testing_CLHIA_Industry_Position_2010.pdf)

<sup>v</sup> The debate about the use of genetic test results relates primarily to *predictive* tests when the symptoms are not yet present as opposed to diagnostic tests to confirm a diagnosis when an individual is already displaying symptoms. The United Kingdom moratorium only applies to predictive tests.

In order to justify collecting and using genetic information, or any other information, in addition to consent an insurance company subject to PIPEDA would need to be able to demonstrate that the information serves a legitimate purpose, that it is necessary for that purpose and that a reasonable person would consider the collection and use appropriate.

## Understanding the Life and Health Insurance Industry

The life and health insurance industry provides a variety of products and it relies on a number of factors to assess an applicant's risk and calculate the appropriate premium. These factors can include the applicant's age, gender, medical status and history, occupation, lifestyle (for example whether the person smokes) family history, and other relevant information.

Patient advocacy groups, such as the Canadian Coalition for Genetic Fairness, and some medical researchers worry that unless the use of genetic information by insurers is controlled, increasing numbers of individuals will be denied coverage or charged prohibitively expensive rates creating the unintended consequence that some individuals will decide not to undergo genetic testing that could benefit them and other members of their family.

The CLHIA believes that an insurance contract is a "good faith" agreement and that it should be able to make use of genetic information on the grounds that it needs to be able to use all relevant information to assess risks accurately and to ensure that the insurance market functions appropriately and fairly for all participants including the entire pool of insured persons.

Both sets of arguments are compelling. While the patient advocacy arguments are intuitive, the industry's claims are much less so. The way in which the insurance industry assesses risks and prices insurance products is technical and complex. The Office of the Privacy Commissioner of Canada commissioned two papers from academic experts to help us assess the industry's arguments that insurers need to have access to genetic information, where it already exists, to accurately and fairly assess risks. We also hope that the two papers will be useful to other stakeholders and contribute to the public debate on this important issue.

The paper by Professor Angus Macdonald, Department of Actuarial Mathematics and Statistics and the Maxwell Institute for Mathematical Sciences, Heriot-Watt University, Edinburgh, Scotland, looks at the relevance of genetic information in the life and health insurance industry from an actuarial perspective. The paper by Professor Michael Hoy, Department of Economics and Finance at the University of Guelph, and Maureen Durnin, examines the potential impact of a ban on the use of genetic information from the perspective of an economist.

## Conclusions from the Papers

The papers by Macdonald and Hoy and Durnin reach a similar conclusion that, at the present time and in the near future, the impact of a ban on the use of genetic information by the life and health insurance industry would not have a significant impact on insurers and the efficient operation of insurance markets.

In reaching this conclusion, both papers distinguish between complex or multifactorial disorders and monogenic (single-gene) disorders. (See the Glossary below.) With respect to multifactorial disorders, they conclude that since the genetic contribution to most common complex disorders and to the risk of mortality from these disorders is small, prohibiting insurers from using results indicating the presence of a genetic mutation for one of these disorders would not adversely affect the financial viability of insurance

markets. Allowing individuals to keep these test results private would not result in significant adverse selection, i.e., individuals purchasing large amounts of insurance relative to those who do not possess such genes.

They conclude that monogenic disorders are so rare that in an insurance market of reasonable size, the cost impact of any adverse selection that might result from restricting access to genetic test results would be very small.

In addition to looking at the impact of a ban from an economic efficiency perspective, Hoy and Durnin also look at the impact from a social welfare perspective, that is, in terms of the welfare of society as a whole. They conclude that even if a ban resulted in a higher price for the many low-risk individuals and a lower price for the fewer higher-risk individuals, the resulting reduction in coverage would not be significant and the ban would improve the overall distribution of well-being from an equity perspective. They suggest that there are important “instrumental benefits” from the privacy protection that would be enhanced by such a ban. Individuals would be more likely to undergo testing, and increased testing not only has the potential to improve an individual’s wellbeing, “it is also possible that the overall health care system could be made more efficient and less costly.”

Both papers acknowledge that their conclusions are based on the situation now and in the near-term given the state of medical and scientific understanding of the relationship between genetic abnormalities and diseases and the relatively small amount of actuarially relevant genetic information currently available. However, both acknowledge these factors may change over time.

## Glossary

**Adverse selection** – a phenomenon that occurs with insurance when individuals base their purchasing decisions on information unknown to the insurer or on information that the insurer may know but is not able to reflect fully into the premium being charged. This can result in individuals at higher risk purchasing insurance at a price, below its true cost, that does not reflect their risk.

**Genetic disorder** – a disease that is caused in whole or in part by an abnormality in an individual's DNA. Many diseases have a genetic component.

**Genetic testing** – at its simplest, it involves testing blood or other tissue to identifying genetic disorders. There is no simple commonly agreed upon definition. Genetic testing can also be used to establish or disprove biological relationships, provide information about ancestry, verify identify and for other purposes.

**Insurance underwriting** – the process of evaluating the risk of insuring a particular person or group of people, based on the probability of adverse events occurring, and setting appropriate insurance premiums. This can also result in a decision not to insure a particular person.

**Monogenic disorder** – a disease caused by a mutation or abnormality in a single gene. The mutation may be present on one or both chromosomes – one chromosome is inherited from each parent. Huntington’s disease and Tay-Sachs disease are two well-known examples. Each child of a parent with Huntington’s disease has a 50 per cent chance of inheriting the disease. Monogenic disorders are relatively rare in comparison with more commonly-occurring diseases. However, the genetic abnormalities that cause monogenic disorders are typically highly “penetrant” which means that if the individual inherits the gene he or she is likely to develop the disorder.

Multifactorial inheritance disorders – a disease caused by a combination of inherited variations in genes, often acting together with lifestyle, diet, environmental and other factors. Most diseases, including heart disease, diabetes, and most cancers are multifactorial. The effect of non-genetic factors such as diet may be greater than the effect of the genetic factor which means that in some cases individuals can take steps, for example by exercising more or altering their diet, to mitigate the genetic impact.