

# Genetics and life insurance in Canada: points to consider

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**T**he 2003 “Public Opinion Research into Genetic Privacy Issues”<sup>1</sup> found that the wide majority of Canadians reject the right of insurance companies to ask for genetic information and this even if applicants have knowledge of a genetic condition.

The position of the Canadian Life and Health Insurance Association 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.”<sup>2</sup>

Over the past year, insurers, patient advocates, researchers and/or clinicians involved in the Genetics and Society Project of the Université de Montréal, Genome Canada projects (Quebec and Ontario) and in the INHERIT BRCA<sub>s</sub> Project (Interdisciplinary Health Research International Team on Breast Cancer Susceptibility, Canadian Institutes of Health Research) met as the Canadian Genetics and Life Insurance Task Force to further the debate on genetics and life insurance in Canada.

Prior to any discussion of possible approaches (IV) or points to consider (V), it is important to note that the whole area of genetics (I) and insurance (II), is a subject that is ripe with misconceptions (III).

## I. Genetics

“Genetic testing can be narrowly or broadly defined. Narrowly defined, genetic tests are those tests that are based on the presence or absence of specific genetic abnormalities. If tests based on the end-products of most genes are included, the definition is broadened enormously.”<sup>3</sup> Indeed, in common diseases such as diabetes, asthma or cancer (as opposed to inherited, single-gene diseases) genetic risk factors are probabilities. Expression of these risk factors is influenced by gene-gene interactions, medical interventions, socioeconomic and lifestyle factors as well as the environment. Under a broader definition, genetic testing may be hard to distinguish from other forms of predictive testing such as blood pressure or cholesterol.

## II. Insurance

A life insurance policy is a contract between the policyholder and the insurer, designed to provide financial pro-

tection in the event of death. The specific provisions of the contract cannot be altered by the insurer once the policy is in force, unless agreed to in writing. While certain policies are offered for a defined term (5, 10 or more years), many last throughout the lifetime of the insured. Provided the policyholder continues to pay the premiums, the policy cannot be cancelled by the insurer.

To calculate the premium required to support the risk, the insurer uses age, gender, health status, lifestyle and family history. The insured is then assigned to a group of other insureds with similar life risks. The premium is based on the risk of dying within any future year. For example, a policyholder will pay more with respect to an insured who is 65 years of age rather than one who is 25 because the former’s probability of dying in any year is higher. Actuarial experience shows that smokers have a shorter life expectancy than nonsmokers of the same age. Similar information about the impact of certain genetic mutations is now emerging.

The process of categorizing persons to be insured into groups with similar risks is called underwriting. By its very nature, this process discriminates between individuals but it is designed to make people pay premiums according to their individual risk status. Those with like risks receive similar underwriting treatment, and thus the policyholders pay similar premiums.

Because underwriting may uncover impairments that result in increased premiums, it is not uncommon for prospective policyholders or insureds to attempt to conceal unfavourable information. This is known as adverse selection. It could result in an applicant paying lower premiums and, ultimately, in insurers paying out more.

Limited family history is requested on many insurance applications. Usually the applicant or other person whose life is to be insured is asked if his or her parents and siblings are alive or dead and, if dead, what was their age and cause of death. Information on health status (including medical history, lab tests and doctors’ reports) and lifestyle (tobacco and alcohol use) are maintained by the insurer in strict confidence. Some medical data are reported to the Medical Information Bureau (MIB). The MIB was established to identify applicants who were rated or denied insurance because of a medical or other impairment and who then applied to a second company but withheld the information which led to the adverse decision.

Finally, it is important to distinguish life insurance from social security, disability insurance, unemployment insurance,

the Canadian pension plan, and the solidarity underlying Canada's universal health care system. The principal role of life insurance is to provide income security for surviving household members in the event of death. Life insurance is a private contract based on selection and risk-spreading according to risk of death of either a primary or secondary income earner, or both.<sup>4,5</sup> It is a contract aimed at offering some form of financial security for unanticipated loss. Ninety percent of applicants for life insurance are insured at standard rates.<sup>6</sup>

### III. Misconceptions

Many misconceptions surround the debate on life insurance and genetics. The task force decided that it was important to put forward certain premises on which all members could agree.

First of all, all individuals carry genes that make them susceptible to diseases. Certain genes may modify risk or protect from risk. Absent tests for single-gene disorders, totally reliable genetic tests are not currently available on the market. Yet, consumers are concerned that, in the future, genetic testing will be used for reasons other than medical purposes. They consider questions pertaining to family history as less threatening than genetic testing. There may, however, be an indirect pressure to undergo genetic testing as a result of family history in order to influence rates. The potential pressure to undergo genetic testing for commercial purposes is seen by many as problematic. Dealing with predictive genetic information can be cumbersome and is a personal decision that has to be made in the context of health care. Genetic information necessarily has familial repercussions. Understanding the significance and impact of genetic testing results is difficult, and therefore, at the present time, genetic information can rarely be effectively used in risk assessment.

Second, life insurance is neither pre-paid health insurance, nor pre-paid medical expenses or social security. Private commercially based life insurance is valued by many and plays an important role in our society. Life insurance is often requested by a financial institution in order to obtain loans or buy a house or car. For a rational policy on the use of genetic information, it is important to determine how restrictions would impact on industry.

Third, genetic information is perceived by the public to be different than other forms of health information. Public perception and concerns cannot be ignored or discounted. There is both a lack of information as well as inaccurate information concerning the issues surrounding life insurance and genetic tests. This does not offer a good basis for a debate on risk assessment.

### IV. Possible approaches

In spite of these misconceptions, current approaches for reform have been put forward or followed in other countries:<sup>7</sup>

1. maintaining the status quo (the market will adjust pre-

- miums as information emerges)
2. imposing a total prohibition via legislation on access to, and/or use of, genetic information by insurers (based on the premise that genetic information is different from other medical information)
3. putting in place a system of regulatory review of the use of new forms of testing and new forms of information, including genetic information (a standing review commission; ombudsman, etc.)
4. undertaking a moratorium (legislative or voluntary) on insurers asking applicants for test results (an approach that recognizes the lack of an actuarial base for the interpretation of genetic test results)
5. promoting a proportionate approach where information would be requested only if the amount of life insurance exceeds the annual income of the applicant, or a threshold approach (below a certain amount no questions would be asked concerning genetic test results), and
6. strengthening privacy reforms (strengthening the protection afforded to medical information generally, and thereby limiting access).

### V. Points to consider

In examining the relevance or possible applicability of these approaches to Canada, the task force noted that it is difficult to distinguish diagnostic genetic testing from any other medical test that gives a definite diagnosis of an existing medical condition. Predictive genetic tests on asymptomatic people or using increasingly refined and informative family histories to determine susceptibility, although necessary for a better follow-up of at-risk individuals, raise concerns. The task force came to the conclusion that genetic testing and research is rapidly developing and is moving toward genomics and proteomics. Thus, defining what is a "genetic" test is difficult.

On the one hand, allowing insurers to use genetic tests as a basis of risk-rating may result in some (high-risk) individuals being discouraged from purchasing "adequate" levels of coverage because of having to pay substantially higher prices for life insurance coverage. In this situation, the role of life insurance as a means of income security for surviving members may be unnecessarily restricted. On the other hand, if regulation prohibits use of genetic test results, this could lead to adverse selection problems and substantial general price increases for life insurance. This may be sufficient to deter all members of the insurance pool, and in particular low-risk members, from purchasing adequate levels of coverage. Again, the income security function of life insurance may be jeopardized.

During this current period of uncertainty, the public fears participating in genetic research and diagnostic testing owing to the possible impact of genetic information on insurability.<sup>8</sup> There is an urgent need for independent, rigorous assessment of when new genetic information is sufficiently valid to be used by insurers with actuarial fairness.

Whatever model is to be adopted in Canada, actuarially sound classification is important. At the same time, it is important to evaluate what the social and medical repercussions of the use of this information will be. Public policy considerations may impose additional restrictions on insurance underwriting. These circumstances should be clarified, when they exist, and restrictions should be the subject of open debate. All elements, including the economic feasibility of such restrictions, should be taken into consideration.

In the context of genetic developments, it could be argued that additional efforts should be undertaken to ensure that people can obtain access to life insurance; whether it be by insurance organizations coming up with a proposal, or government working together with insurance.

To that end, the task force agreed on the need to debate the following two avenues:

- A. Not use genetic test results (excluding family history) for a set, moderate amount of insurance coverage for a limited period of time (5 years). This amount and time limit could be revised if warranted.
- B. Create an independent standing body that includes consumers, government, clinicians, industry and researchers for ongoing review of criteria concerning the reliability of genetic information for underwriting purposes. This advisory body could also handle complaints and queries from consumers.

Measures such as these would ensure an ongoing debate on both the role of the life insurance industry and on the meaning of genetic research, testing and information. Most importantly, these two measures would stimulate discussion in Canada on a subject that affects a value that Canadians hold dear: the universal health care system. Canadians

should be able to avail themselves of the health benefits of the genetic revolution without fear.

The authors are members of the Canadian Genetics and Life Insurance Task Force. Bartha Knoppers is chair, Trudo Lemmens and Béatrice Godard are co-chairs, and Yann Joly is coordinator of the task force.

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