

Can't Always Get What you Want? Try an Indirect Route you Just Might Get What you Need: A Study on Access to Genetic Data by Canadian Life Insurers

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Abstract: Concerns about genetic discrimination (GD) have been reported since the 1980s. The potential chilling effects of GD both in the clinical and research settings have prompted the adoption of a myriad of laws and moratoria on access to genetic data in Europe and the United States. Recent studies in Canada, Australia and Germany concerning patients and family members at-risk for Huntington's disease have raised concerns about GD and life insurance. However, broader empirical evidence on the occurrence of GD (ex. involving complex genetic disorders in the context of personalized medicine) remains scarce. This study identifies the information that Canadian life insurers request in their primary proposal forms. 21 forms from different insurers, available online, were assessed to determine 1) whether insurers are explicitly or specifically requesting genetic information from applicants, 2) whether insurers are using open-ended questions in a way that may compel the broad disclosure of personal information, and 3) what type of authorization is requested from applicants to enable insurers to verify the accuracy and completeness of the information submitted on the form. Our findings show that Canadian life insurers do not explicitly request that applicants disclose their genetic test results on insurance questionnaires. However, their use of broad terminology and open questions, provide them access to a wealth of medical information (including genetic test results) in addition to family history of diseases. Both the breadth of information currently being collected through their proposal forms and the lack of standardization across insurance groups raise concerns about the equity, transparency and overall coherence of the process. Although the findings have to be interpreted in the context of the inherent limitations of this type of study, they carry important consequences for the translation of personalized medicine which requires and generates a wealth of genomic information for patients.

Keywords: Canada, DTC, genetic discrimination, genetic information, health data, life insurance, privacy.

1. INTRODUCTION

Recent discoveries in the field of genetics have generated a wealth of information, enabled a better understanding of the causes of certain diseases, allowing the development of better tools for prevention, screening and treatment in the context of personalized medicine. Essentially, genetic information may be generated from family history and genetic test results performed in the context of clinical care, research, or direct-to-consumer (DTC) internet diagnostic services. The use of genetic information by third parties outside of the therapeutic context remains controversial. For example, the potential use of genetic information by life insurers to classify people in different risk group (ex. High risk), for the purpose of establishing the applicant's insurability (*i.e.* verifying the applicant's health status in order to confirm his/her coverage eligibility) and availability and price of life insurance policies, has raised concerns [1-3]. These concerns are embodied by the notorious concept of "genetic discrimination" (hereafter "GD"), the differential treatment of an individual from other

members of a group on the basis of his/her genetic characteristics [4]. However, precise definitions of GD tend to vary in the literature and can be more or less restrictive depending on the specific context [5]. Despite the scarcity of evidence of a systemic GD practice by life insurers outside of the specific context of Huntington's disease (hereafter "Huntington") [5], many countries have adopted broad laws, moratoria and policies preventing insurers from accessing genetic information [6, 7]. These laws enacted to prevent GD vary widely in scope depending on the way they define "genetic information" or "genetic tests". For example, a broad formulation could include "family history of diseases" which is an important source of genetic information while a narrower one could be limited in application to the results of "DNA testing" for specific diseases.

1.1. Context

In Canada, where no specific laws have been adopted to prevent insurer's access to genetic information, little is known about the practice of the industry. According to the Canadian Life and Health Insurance Association Position Statement on Genetic Testing, "insurers would not require an applicant for insurance to undergo genetic testing. However, if genetic testing has been done and the information is avail-

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able 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" [8].

Under Canadian law, a life insurance contractual relationship is based on the principle of good faith (utmost good faith in Quebec civil law) whereby the applicant is required to disclose "all the facts known to him which are likely to materially influence an insurer in the setting of the premium, the appraisal of the risk or the decision to cover it" [9]. In turn, the insurer is required to provide a coverage amount based on the fair assessment of the applicant's risk [3]. According to insurers, these requirements are meant to ensure actuarial fairness and prevent adverse selection. Adverse selection can be described as the process where people presenting a higher risk would seek more extensive insurance coverage based on information known to them but not shared with their insurer [10]. If adverse selection was to materialize on a large scale, it would have a very detrimental impact on the private insurance model. This explains why, in private insurance, it is seen as important that risk classification "accurately reflect[s] the cost of a given risk characteristic; be applied objectively and consistently; and be cost-effective and responsive to change [and scientific developments]" [11, 12]. Therefore, applicants who fail to comply with the legal obligation to make a full and frank disclosure of all known relevant risks at the time of the application, may see their life insurance contract annulled by the courts at the request of the insurer [2, 13]. As we can see, the duty of disclosure may go beyond responding accurately to questions asked on the life insurance proposal forms.

Nevertheless, life insurance proposal forms are fundamental contractual documents used to facilitate the disclosure process. These forms contain a questionnaire (or declaration of insurability) dealing with the health and socio-economic context of the applicant. These forms are the first source of information used by insurers to assess applicants' coverage eligibility (insurability) and determine their premium amounts. Depending on the sum to be insured, the age and the health of the applicant a medical examination as well as some additional medical tests may also be required by the insurer [14]. Considering this, it appears that the proposal forms are very good documentary resources to determine which type of personal information about the applicant is primarily sought by insurers for the purpose of concluding a life insurance contract. This study aims to analyze the information requested through primary life insurance proposal forms in Canada to determine whether life insurers are actively seeking to obtain genetic data through questions included in these documents. Since popular anxiety over possible access to genetic test results by insurers has been identified as a recurring issue that could impede the realization of personalized medicine [10, 15], it appears of primordial importance to better document the practice of insurers on this particular matter.

2. MATERIAL AND METHODS

2.1. Identification and Selection of Eligible Life Insurers

A list of 133 life insurance companies was compiled between March and August 2012 from listings provided by

Assuris (a not-for-profit organization with whom all insurance companies in Canada are required to register) [16], the Canadian Life and Health Association (a voluntary industry association comprising 99% of Canada's life and health insurance business) [17], and the Autorité des Marchés Financiers (the financial market authority of Quebec – "AMF") [18]. Two more companies were added in March 2013 increasing our total listing to 135 insurers.

We developed and applied a set of criteria to identify eligible life insurance providers from the list previously compiled: eligible insurers are insurance companies that are in business, have a website, and offer life insurance products and services to Canadians. Insurers who are primarily reinsurers or who provide life insurance to a restricted number of customers due to non-health related criteria (*e.g.* selective membership on the basis of religion, profession or national origin) were excluded from the study. Affiliated insurers were grouped together as one entity unless each company was determined to be using independent and distinct primary insurance proposal forms. 38 eligible insurers were identified this way, but only 21, whose proposal forms were available online were retained for our study. For an overview of the search and selection strategy, (Fig. 1).

2.2. Data Extraction from the Applications Forms

The proposal forms were obtained by INF and YJ between March and June 2012 through keyword searches on the identified insurers' websites using the terms "form(s)" or "formulaire(s)". The forms were assessed for relevance from June to August 2012. The forms collected cover a great range of life insurance products including universal life, term-life, life and critical illness, mortgage life and group life. There is also a great variety of organization and content between the different life insurance proposal forms. For example, some forms include a section containing the declaration of insurability within the same document while others have separate forms to be completed and submitted depending on the type of product; some forms are specific to a province or a region, while others are applicable nationwide. Therefore, we analyzed the forms through a social science comparative approach that incorporates both descriptive analysis and qualitative content analysis with direct thematic coding. Data from the forms was collected to investigate three main questions: (1) whether life insurers are explicitly or specifically requesting genetic information and if so what kind; (2) whether proposal forms contain generic questions or other language that would implicitly require the disclosure of genetic information, and (3) the existence and content of any contractual clauses (*e.g.* waiver of confidentiality) included in the application form to allow insurers to verify the information provided in the application with third parties in order to ensure the completeness and accuracy of the information collected. The results obtained were analyzed and, where appropriate, converted to statistical data. Information presented in the tables provided constitutes the primary basis for all statistical results and analyses.

3. RESULTS

Our findings are based upon 21 independent proposal forms from Canadian life insurers, which were issued

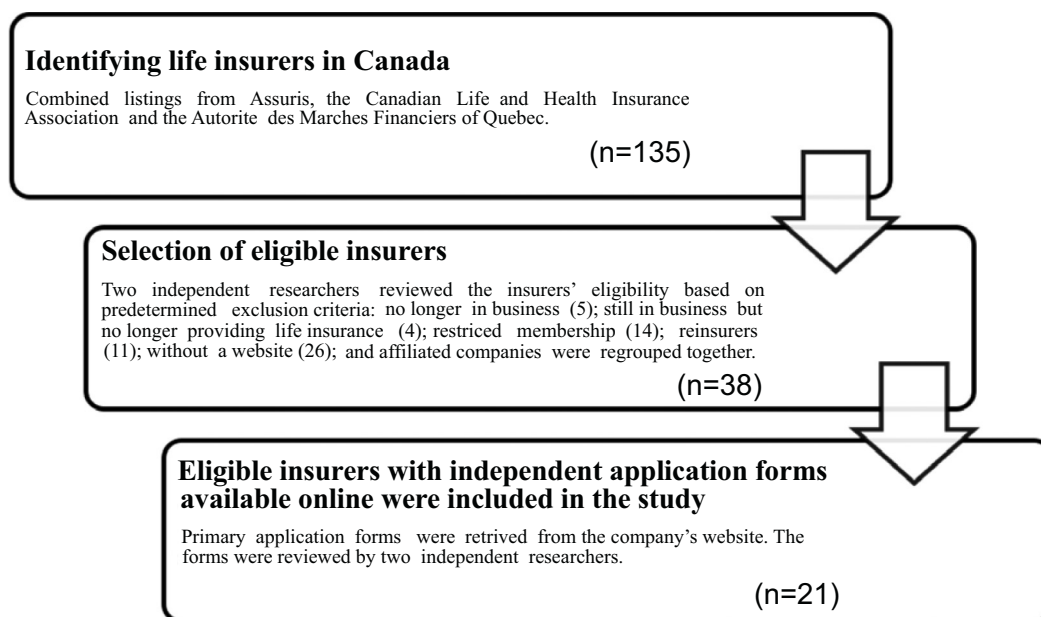


Fig. (1). Identification and selection of life insurance companies.

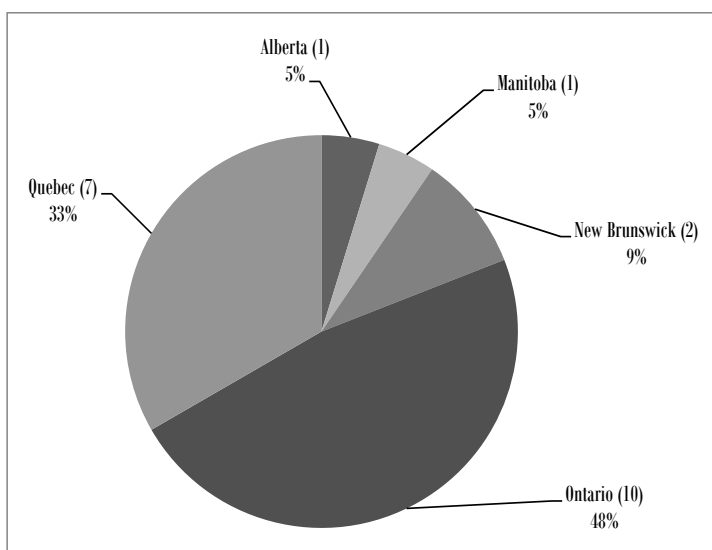


Fig. (2). Geographical representation of the 21 life insurers based on their headquarters.

between 2001 and 2012. While most life insurance companies provide services across the country, the majority (81%) have their headquarters in Ontario or Quebec, Canada's two most populous provinces. The other insurers are located in Alberta, Manitoba and New Brunswick (Fig. 2).

3.1. Information Explicitly Requested

While there is some degree of variability among general questions regarding medical information, a selected number of common inquiries are presented in Table 1. Only one insurer does not request any health information in its application form. This is the only form available from this insurer and it pertains to a group life insurance product. There is a note on the insurer's website stipulating that coverage is contingent upon admissibility to the program.

3.1.1. Terminology

The 20 insurers inquiring about medical information use different terms often in combination. While 30% (6/20) solicit information relating to any "investigation", 65% (13/20) inquire about any "examination". The broader general term "test" was employed by 13 insurers (65%) either alone or in combination with the aforementioned words. The terms "analysis" and "special exam" were each used by one insurer.

Among the 20 insurers asking about tests/examinations/investigations completed, pending or recommended, 75% (15/20) request information on diagnostic tests and 55% (11/20) ask specifically about blood tests. Only 10% (2/20) require the disclosure of "screening test" results. Although none of the insurers inquire specifically about genetic test

Table 1. Health information and consent requested.

Information requested	No. of insurers
Insurers using the terms “genetic disease”	1
Insurers using the terms “inheritable disease”	1
Insurers using the terms “hereditary disease”	10
Genetic test results	0
Genetic test results of a family member	0
Family history of diseases (all inclusive)	17
Family history and any type of test done, pending or recommended	17
Family history of diseases from “immediate” relatives	17
Family history of diseases from “immediate” and other relatives	6
Screening test results	2
Diagnostic testing done, pending or recommended	15
Blood test done, pending or recommended	11
Any test done, pending or recommended	13
Any type of test /investigation/examination/ done, pending or recommended	20
No medical information requested	1
Broad consent required to access and share information with various third parties (healthcare professional, financial institution, etc.)	21

results from applicants or their relatives, 95% (20/21) request information on diagnostic, blood or other tests completed, pending, recommended or contemplated. A selected number of terms are presented in Table 1. Importantly, none of the proposal forms reviewed included definitions of the terminology used for the questions.

3.1.2. Family History of Diseases

An important number of insurers, 81% (17/21), ask for information on family history of diseases. Based on the indications provided in the forms, we identified two types of questions on family history. The first type concerns relatives often referred to as the applicant’s “immediate” or “biological” family. Those questions include parents, spouse, brothers, sisters, and children (or dependents) as examples. All insurers seeking family history seek information on relatives from this group. The second type of question asked by a minority of insurers, 35% (6/17), seeks information that includes more than “immediate” relatives. These questions request information regarding extended family members such as grand-parents, aunts and uncles, or use broader terminology such as “in your family” or “familial history”. Additionally, a number of forms use the term “dependents” rather than “children” and do not ask the applicant to specify a biological relationship with these individuals.

Among the 17 insurers inquiring about the family history of applicants, 70% (12/17) provide applicants with a non-exhaustive list of medical (genetic) conditions of particular interest to them. Only five companies (29%) provide an exhaustive listing of conditions. The conditions most listed by

insurers are summarized in Table 2. There is an important heterogeneity of both the proposal forms and the specific sections where information on diseases is requested (in different part of the application, cited several times within the same application, or requested on a separate insurability document). Nevertheless, the list of all conditions explicitly mentioned by insurers includes: AIDS/HIV; alcoholism; Amyotrophic Lateral Sclerosis (ALS or Lou Gehrig’s disease); arthritis; advanced loss of hearing; advanced ophthalmic disease; breast cancer; cancer (and tumor); chronic or progressive kidney, lung or liver disease; colon polyposis or cancer; cystic fibrosis; diabetes; heart disease; hemophilia; hepatitis; high blood pressure; high cholesterol, Huntington; mental disorders (with hospitalization); hypertension; mental or nervous disorder (including Alzheimer’s disease); motor neuron disease; muscular dystrophy; multiple sclerosis; osteoporosis; Parkinson’s disease; polycystic kidney disease; retinitis pigmentosa; Steiner’s disease; suicide; stroke; transient ischemic attack (TIA); tuberculosis; and urinary disorder.

3.1.3. Consent to Verification via Access and Sharing of Information with Third Parties

All proposal forms, irrespective of the type of product they cover, contain a similar data access and sharing clause enabling the insurer to verify the information provided by the applicant with their doctor (or other third parties). Selected sample clauses are presented in Table 3. While the language used varies among insurers, these clauses share a similar objective: to require applicants to consent to insurers having access to the applicant’s health and lifestyle-related

Table 2. Family history information most requested.

Diseases	No. of insurers
Diabetes	17
Cancer	16
Heart disease	16
Huntington	13
Parkinson	9
Alzheimer	9
Neuron Motor Disease	7
Amyotrophic Lateral Sclerosis (ALS)	6
Insurers providing non-exhaustive list conditions	12
Cancer	12
Heart disease	12
Huntington	10
Insurers providing an exhaustive list of conditions	5
Cancer	4
Heart disease	4
Huntington	3

Table 3. Selected data access and sharing clauses.

	Consent clause included in primary proposal forms for life insurance
Sample 1	<p>I authorize any physician, health care professional, hospital, clinic or other medical or paramedical establishment, as well as any insurance company, the Medical Information Bureau, a credit agency, and any other organization, institution or person that holds records or information pertaining to me or my health status, or pertaining to my children and their health status (when an insurance application on the life of a child is requested) to exchange such records or information with [The Insurance Company] or its reinsurers for underwriting and claims adjudication purposes. (...)</p> <p>I authorize [The Insurance Company] to retain the services of an investigator at the time of underwriting and during the claims process. This investigation, when necessary, may consist in obtaining information on my health, finances and lifestyle.</p> <p>In the event of a claim, I authorize any coroner, police force and any other agency that holds information regarding my death to communicate such information to [The Insurance Company] and its reinsurers. (...).</p>
Sample 2	<p>I hereby authorize any physician, practitioner, hospital, medical or paramedical clinic, insurance company, the Medical Information Bureau or any other organization, institution or person having any information about me or my children concerning our health or insurability, to provide such information to the [Insurance Company] or its reinsurers in order to evaluate my eligibility and insurability or that of my spouse and my dependents, if any, under this plan. I agree that an investigation report regarding myself, my spouse and my children may be requested.</p>
Sample 3	<p>I authorize any health professional as well as any public or private health or social services establishment, any insurance company, the medical information bureau, personal information agents or investigation and security agencies, my employer or ex-employer as well as any public organism detaining information to transmit it to the insurer, to its reinsurers and their service providers if necessary, for risk evaluation or to study any claim.</p> <p>I also authorize my insurer, or its reinsurer to exchange with other insurers or other persons that I have indicated as references, the personal information contained in the present application and to question them for the purpose of risk evaluation or claim adjudication.</p> <p>The insured agrees to collaborate and sign any required specific authorization document that could be required or necessary to obtain the information enabling the insurer to adequately evaluate the situation. (...).</p> <p style="text-align: right;"><i>(translation from French by the authors)</i></p>

information, from medical institutions or from any stakeholder having a file on the applicant, for the purposes of preventing misinformation and fraud that would impact the determination of coverage eligibility and the setting of the premium.

3.2. Vague and Open-Ended Questions

In addition to specific questions on family history of diseases, the majority of insurers (76%; 16/21) use a variety of vague or open-ended questions (sometimes in com-

Table 4. Questions potentially requiring the disclosure of genetic information.

Open-ended questions	No. of insurer
Have you ever had any known indication of (disease)...?	3
Have you ever sought medical advice on (disease)...?	3
Have you ever been told that you could have (disease)...?	1
Aside from a doctor have you seen any other health professional/practitioner (including counselor)?	13
Do you have a referral, testing, treatment or investigation pending or contemplated	1
Declare you have ever sought medical advice on (diseases)	1

bination). These questions are summarized and presented in Table 4.

Among the insurers using generic questions, 81% (13/16) request applicants share information on their interactions (visits, consultation, or advice) with health practitioners or professionals including counselors (specific expertise of counselor not specified in the forms) but not limited to physicians or doctors.

4. DISCUSSION

Our study has found that Canadian life insurers do not explicitly or specifically request information on genetic test results in their primary proposal forms. Nevertheless, these questionnaires contain broadly-formulated questions, which can provide life insurers with access to a wealth of medical (including genetic) and non-medical information on the applicants and on some of his/her family members.

4.1. Genetic Information and Family History

Generally, questionnaires used by life insurers (as with other types of personal insurance) contain questions not only about the applicant's health and life style, but also about family history of diseases [19]. The aim of these questions is to determine whether there are hereditary conditions that are more likely to affect the applicant's health status. It should be noted that detailed family history of diseases have been considered an important source of genetic information which, in some cases, may constitute a more accurate prediction of future health than the results of many current genetic tests [20].

Thus, it is not surprising that our investigation identified diabetes, cancer, heart disease and Huntington as the most frequently explicitly-requested information on family history of diseases by Canadian life insurers (See Table 2). Indeed, Huntington is a highly penetrant, familial, late adult-onset monogenic condition and cancer, diabetes and heart disease are conditions also known to have some strong genetic components. In addition, studies in the United States, Australia, Germany and Canada have raised concerns about GD towards patients and their family members at-risk for Huntington in the context of life insurance [5, 21-25]. Our study also confirms that Huntington is in fact a condition of great interest to Canadian life insurers, as 13 out of 17 insurers seeking family history information explicitly list this condition in their inquiry.

It is interesting to note that while these types of questions will often provide insurers with information on the genetic characteristics of insurance applicants, some of the countries that have adopted laws to restrict access to genetic results still authorize insurers to use questions on family history [26]. A recent *Bill on Genetic Discrimination* introduced to the Canadian Senate (S-201) follows this legislative current by using the expression of "genetic testing" narrowly defined in the Bill to exclude family history from its scope [27]. This quandary speaks to the difficulty and relevance of trying to distinguish genetic information from other type of health or personal data in our laws. Therefore, as it currently stands in Canada, questions on family history can be used by insurers to obtain genetic-related information without having to explicitly or specifically request genetic test results from applicants and their family members.

While family history may provide information that is relevant to assess insurability, we notice that when seeking information on additional individual(s) included in the applicant's request for coverage, some insurers use the term "dependents". This sort of terminology may lead applicants to provide insurers with information on adopted children or other biologically unrelated dependents. The underwriting value of this type of non-genetic familial information, if any, would need to be more clearly demonstrated by actuarial studies. In the meantime safeguards should be built in proposal forms to ensure that if familial risk is actuarially relevant, then only information from biological relatives should be requested and/or taken into account.

4.2. Broad and Vague Terminology

In addition to requesting family history of diseases, life insurers are using broad language and vague terms to solicit the most information possible from applicants. Through this line of inquiry, there is a possibility that insurers will be provided with genetic information. For example, questions worded to seek information on "test(s)", without any additional indication (see Table 1), are broad enough to be interpreted as encompassing predictive or diagnostic tests (including genetic tests), pharmacogenetics tests as well as blood tests. Such findings are consistent with the results of previous investigations of life insurance practices in the United States and Canada dating back as early as the 1990s. Indeed, studies by McEwen *et al.* confirmed that many life insurers, even when they were not performing or requiring genetic testing, were routinely asking questions concerning

family history of diseases and requiring laboratory test results (ex. blood test results), which may reveal genetic data [14, 28]. Interestingly, the Council of Europe recently positioned itself against the inclusion of such broadly formulated questions in insurance questionnaires as it feels it could compel applicants to disclose more personal information than what is needed for insurance underwriting purposes and is inconsistent with current European data protection legislation [29].

Moreover, the proposal forms do not make any distinction between the different contexts in which these tests could have been conducted. Because the term “test(s)” is used generically, it could be understood to include tests done on the applicant in the research context. This is problematic because genetic test results obtained in the context of research may not meet analytical validity, clinical validity and clinical utility requirements or other applicable legal requirements to approve genetic tests for clinical use [30, 31]. Research results can be very difficult to interpret [12], and will often be contradicted by later studies. Studies have shown that concerns about insurers’ access to genetic test results completed in the research context have had a negative impact on research participation [15, 32, 33]. It also contributes to the negative perception of genetic studies as being associated with substantial risks of psychosocial harm by research ethics committees [34]. A similar argument can be made about genetic test results obtained through DTC products. These test results may raise similar issues as genetic testing in the context of research as they may not have been disclosed to or interpreted by the applicant’s physician [35]. Consumers using DTC already face many challenges in assessing or interpreting these test results [36], which will present additional issues for them in determining whether such genetic test results are material information for insurance purposes. Those issues are all the more relevant in the current context where whole genome sequencing is being increasingly used in the research context and introduced in the clinical practice raising major questions about what should be done with the incidental findings [37-39]. Applicants may not even be aware that when applying for life insurance they may be required to disclose these test results on the insurance proposal forms.

Canadian proposal forms also include several questions regarding visit(s) to or advice received from a “health professional” or a “counselor” (see Table 4). These questions could be interpreted broadly to include genetic counselors and geneticists. A similar line of questioning was identified by Lynch *et al.* in a 2003 Australian survey of primary life proposal forms [40]. We note that the Lynch study, which also included 21 insurers, identified 9 insurers asking questions about “other health professionals”, while our study accounted for 13 such insurers. This may be reflective of the increased availability of genetic test results since 2003.

Our study also found that Canadian life insurers are using general and open-ended questions which enable them to request information beyond what is included in the applicant’s medical file. In accordance with these findings (see Tables 1 and 4), a review of life insurance proposal forms in Australia had also revealed that questions used by insurers had become

more searching: for example, by seeking information on tests that the applicant was *considering* or had been *advised* to undergo [41]. Otlowski estimated that this new approach may be aimed at discouraging individuals from taking out life insurance before getting tested in order to avoid the duty of providing the results to insurers [41, 42], a practice sometimes recommended by genetic counselors and geneticists. For example, since Canadian life insurers will seek genetic test results, as stated in their policy statement on genetic testing [8], applicants and their family members may therefore be inclined to secure insurance before seeking medical advice on genetic testing from a professional or even before undergoing recommended clinical genetic testing.

In addition to these concerns, generic and open-ended questions asked by Canadian life insurers may raise other issues. For example, 33% of insurers used questions such as “have you ever been told that you could have a particular disease?” or “have you ever had any known indication that you could have a particular disease?” which do not specify whether the information they seek was provided by a health professional. Therefore, applicants may even feel required to disclose information obtained from non-medical sources such as family members and DTC genetic test providers. The first possibility is particularly troubling because it could discourage family members who have been tested from sharing information with their (at-risk) relatives since they, in turn, may be required to disclose this information to the insurer. The second possibility carries the risk that insurers would make insurability decisions based on the results of tests which have been consistently associated with significant technical and ethical issues by academic studies [43-45].

As previously seen, applicants are currently required by Canadian law to disclose to the insurer every fact within their knowledge which are likely to materially influence the determination of the premium, the appraisal of the risk or the decision to cover it [9, 46-49]. Thus, knowing genetic information that is not material does not impose the applicant the obligation to disclose it on the application form [50]. However, assessing what constitutes “material information” may be a very difficult exercise to undertake for patients and their family members. In addition, it has been suggested that in jurisdictions where there are no legal provisions restricting life insurers’ access to genetic data, insurers should forebear access at the very least to genetic test results obtained in the context of research or private DTC [12].

4.3. Broad Clauses and Privacy Concerns

Proposal forms usually contain a standard data access and sharing clause, which gives the insurer written consent from the applicant to verify all medical data with his/her physician including details of any clinical notes [51]. It also authorizes the communication of any data contained in the applicant’s declaration of insurability to the Medical Insurance Bureau, a North American data repository used by insurers to prevent fraud and misrepresentation [19]. This authorization also constitutes a valid waiver of the applicants’ confidentiality rights, which enables the insurer to access and share their information with third parties for the purpose of assessing insurability or preventing fraud.

Our study demonstrates that the data access and sharing clause included in some life insurance proposal forms is overly broad and may provide life insurers with access to data beyond that which is necessary for the applicant's insurability assessment (see Table 3). For example, applicants are asked to consent to the insurer having access to and sharing information obtained from "any other organization, institution or person that holds records or information pertaining to [the applicant]". This type of clause could result in the insurer receiving much more personal information than authorized under current privacy laws [52]. Since the data access and sharing clause (*i.e.* the waiver of confidentiality) is one of many clauses included in complex application documents, when signing the forms, applicants are often not fully aware of the implications that this waiver may have [26].

Finally, the great heterogeneity of the various proposal forms analyzed in this study should be mentioned. Although the proposal forms targeted similar broad types of personal information, the specific language used in each of them, including the more complex terminology selected, differed significantly.

5. STUDY LIMITATIONS

This research was made particularly challenging by the prevailing lack of transparency surrounding the underwriting process, likely due to the competitive nature of private insurance. For example, it was not possible to determine if, following some of the disclosure made on the proposal forms, insurers could at an ulterior stage of the process require additional genetic information or test results in a more specific or explicit manner. We have also noticed that while some additional proposal forms are sometimes available online, they are only accessible through secure websites restricting their circulation. Nevertheless, this research provides an appreciable sample to form a first assessment of the current practices of life insurers in Canada. It is hoped that this initial study will stimulate the interest of the insurance industry to collaborate on future studies on this topic.

6. CONCLUSION

Investigating the type of information sought by life insurers in their proposal forms has provided some valuable insights on the current insurance practice in Canada. Our inquiry has confirmed that life insurers are not specifically or explicitly seeking information pertaining to genetic test results in their primary proposal forms. However, we have identified a number of elements of concerns that warrant further independent studies of life insurance underwriting practices. The questions and language used by insurers are very broad; this terminology may provide insurers with more information than necessary to properly underwrite a life insurance contract, and may discourage applicants from getting tested or participating in genetic research before taking up life insurance. This is all more concerning at a moment in time where health and genomic research, on a national and global scale, aims for the development and clinical integration of personalized medicine. If corroborated by other studies, this scenario may suggest a need for insurers to revise their standard proposal forms to ensure greater conformity

and coherence. There is also a need to document how life insurers use the information they collect. An evaluation of these elements is a pre-condition to fully grasp the extent, if any, of GD in the context of life insurance within countries that have not yet adopted laws or policies preventing access to genetic data. Ideally, these inquiries should not be limited to the phenomenon of "genetic discrimination" but on the use of all types of health and other personal data by the insurance industry.

ETHICS STATEMENT

Not applicable.

CONFLICT OF INTEREST

The authors confirm that this article content has no conflict of interest.

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LIST OF ABBREVIATIONS

DTC	=	Direct-to-consumer
GD	=	Genetic Discrimination
Huntington	=	Huntington's disease

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