Nicholls SG, Joly Y, Moher E, Little J. (2014) Genetic discrimination and insurance in Canada: Where are we now? *On The Risk*. 30(3): 46-52

Title: Genetic discrimination and insurance in Canada: Where are we now?

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Executive Summary

Whole genome sequencing makes risk assessment for common diseases a realistic scenario and has led to renewed interest in the use of genetic information for life insurance underwriting. Despite the debate there is little empirical evidence. There is currently no Canadian legislation that explicitly prohibits access to genetic data for the purposes of underwriting by life insurers, although several recent bills have been introduced for this purpose. In this paper we review the arguments, the evidence and the state of Canadian legislation regarding genetic discrimination and life insurance underwriting. Addressing concerns about the potential for genetic discrimination is not just a question of academic or legal interest. If the public and patients are reticent about who might be able to access genetic information, then they may forego the opportunity of screening or testing and the associated health benefits.

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Biographies

Stuart Nicholls is a Canadian Institutes of Health Research (CIHR) Postdoctoral Fellow at the Department of Epidemiology and Community Medicine, University of Ottawa. His research revolves around public health ethics and in particular the issues arising from the integration of genetic and genomic technologies in public health.

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Julian Little is Canada Research Chair in Human Genome Epidemiology, and Chair of the Department of Epidemiology and Community Medicine, University of Ottawa. His research interests lie in human genome epidemiology, where he is helping develop the techniques that will be needed to translate genetic discoveries into opportunities for preventive medicine and public health benefits, particularly in relation to birth defects and cancer.

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Introduction

The advent of low-cost whole genome sequencing may enable genomic risk assessment for common diseases such as heart disease, diabetes, and some cancers, and the potential for "personalized medicine". Recent discussions regarding the inclusion of whole genome sequencing within newborn screening programs[1] has further prompted debate on the clinical validity and utility of genomic information, but also the rights of children to an 'open future'.[2,3] In addition, pressure from patient groups, in the wake of the 2008 *Genetic Information Nondiscrimination Act (GINA)* in the United States, has led to renewed interest in how genetic information might be utilized for the purposes of private insurance underwriting.[4]

While practice varies internationally, some jurisdictions have enacted legislation in an attempt to address concerns. Most notably, GINA in the United States prohibits group health plans and health insurers from denying coverage or charging higher premiums to healthy individuals based solely on genetic test results. However, this is somewhat of an anomaly that stems from the role of private health care insurers in funding health care services in this country.[5] A more widespread issue is the use of genetic test information for life insurance underwriting;[i] several countries, such as the UK, have taken steps to limit the use of genetic test information for this purpose.[6-8]

The question of appropriate access to genetic test results not only raises legal and ethical issues, but is important with respect to health service delivery: if potential patients (i.e. those not already diagnosed with a genetic condition) are reticent about who might be able to access genetic test results, they may forego the opportunity of testing that could be relevant for their clinical care.[9] Secondly, while there have been a number of proposed bills, it remains an open question whether the proposed legislation would provide adequate protection against the purported (mis)use of genetic information and genetic discrimination. Policy makers must consider whether bills cover different types of hereditary information equally (e.g., is family history treated the same way as genetic test information?), whether all genetic conditions would be covered, or just highly penetrant monogenic conditions, and the appropriate penalties for non-compliance.

Concerns regarding insurance discrimination: the arguments

Legislative approaches are framed in a manner that often results in genetic exceptionalism, i.e., treating genetic information differently from other types of medical information. But can the distinction between genetic and non-genetic conditions be upheld in a post-genomic era? Our expanded understanding of genetic susceptibility implicates a genetic role in more common diseases such as heart disease, diabetes, and some cancers. Indeed, arguments set out by the life insurance industry, and others,[10,11] has been not to accord a special status to genetic (and genomic) information: they argue that legislating to prohibit the use of genetic information fosters unfounded genetic exceptionalism.[11-14] Green and Botkin, for example, have argued that a number of claims made about genetic test information can be equally applied to non-genetic medical information.[11] Further, Malpas argues that even the line of argument about the lack of control over risk– pure genetic bad luck – can be extended to non-genetic conditions, arguing that HIV status is legitimately used in underwriting, irrespective of why the individual is at

[i] Similarly, concerns may also be raised in the context of critical illness cover and long term disability insurance. We limit our discussion here to life insurance purely for simplicity and because this is the context in which recent bills have been raised.

risk.[15] Moreover, the technological advances that have led from targeted genetic testing to whole genome sequencing further blur the distinction between genetic and non-genetic conditions, with the multifactorial and epigenetic nature of diseases potentially making distinctions between genetic and other health data extremely complex.[16]

In contrast, some authors point to difficulties in evaluating genetic information with respect to analytical validity, clinical validity, and clinical utility,[17] as well as the potential for misapplication of test results as a reason for being cautious in the use of genetic information for underwriting purposes. Several authors refer to the example of HIV status in the 1980s, suggesting that assumptions regarding HIV status were used to unfairly discriminate against individuals.[18] Thus, in the context of whole genome sequencing, the complexity of information and potential for incidental findings, or variants of unknown significance, may preclude the accurate appraisal of genomic information. For these reasons, genetic and genomic information should not be available to insurers for the purposes of underwriting. It has also been suggested that another important reason for restricting access to genetic risk information is based on the principle of solidarity.[18,19] Indeed, in some European countries, the recommendation or requirement to obtain life insurance when seeking loans or mortgages has led some to consider life insurance an essential social good,[4,20,21] and thus support the prevention of access to genetic data on the basis of social justice arguments. Consequently, they argue that some basic level of life insurance should be universally accessible.[18,22] Welfare concerns premised on the status of life insurance as a social good may point to wider policy or legislative responses that broadly define the appropriate scope of access to insurance and legitimate information that may be used for assessment. These responses may include decisions regarding genetic information, but are unlikely to be limited to the use of genetic information and may well lead to more generic policy or legislation applicable to the complete spectrum of health information.

Concerns regarding insurance discrimination: the evidence

Whilst the issue of discrimination is often raised in discussions of genetic testing,[23-31] there is a paucity of research on the effects of testing on insurability. A Genome Canada Policy Brief noted that it is often unclear whether reported discrimination is actual or perceived, or whether it is the result of general information about inherited conditions (such as family history) as opposed to genetic testing, *per se*.[32] Goh et al.,[33] report that a third of respondents in a survey of individuals who had undergone testing for the Huntington gene reported some form of genetic discrimination. Of these, 10 individuals (16% of the total sample) reported being denied life insurance. However, it is not clear if this denial was due to family history, or to genetic test results. In a pan-Canadian study, again with participants with a family history of Huntington's disease, less than a third of individuals reported insurance discrimination, and no differences were found between those who had undertaken a genetic test and those who had not.[25] These results suggest that family history may be as important – if not more so – than results of genetic tests, given that many genetic conditions are hereditary. Further, a recent systematic review argued that while the available data clearly documents the existence of individual cases of genetic discrimination, the existing methodologies used are not sufficiently robust to clearly establish either the prevalence or the impact of discriminatory practices. Moreover, the body of evidence to date has been largely developed around a small number of 'classic' genetic conditions that are limited in number but highly heterogeneous. The authors conclude that "the small number of reported genetic discrimination cases in some studies could indicate that these

incidents took place due to occasional errors, rather than the voluntary or planned choice of the insurers."[34]

Despite a lack of clear evidence regarding *actual* discrimination based on genetic test results, several studies indicate that a *fear* of discrimination may impact on the use of clinical genetic tests.[4] A study of one Canadian province found that approximately 60% of respondents indicated that privacy and discrimination fears would influence their decision to undergo genetic testing,[35] although this effect has not been observed consistently.[36] In a conjoint analysis of hypothetical testing scenarios in African American and white residents in the US, Armstrong *et al* found the requirement to disclose results of a genetic test to an insurance company significantly reduced the likelihood of individuals undergoing a genetic test for cancer.[37] This was also found in a similar study in Australia, which has a universal access health care system, in a study in which participants undergoing genetic testing could choose to decline receipt of test results. The indication that genetic test results would have to be disclosed for the purposes of life or disability insurance led to participants being over two and a half times more likely to decline their genetic test results than when this was not indicated.[38]

However, a shortcoming of these studies is their lack of comparison group – there was no examination of other types of (non-genetic) tests. Some studies suggest that privacy of personal health information and access by the insurance industry may be a general concern of individuals, rather than a genetics-specific concern.[39-41] In a survey of consumers of health technology, 75% of respondents indicated that concern about privacy of information was a potential barrier to them using a personal health record (i.e., a website in which consumers can view, maintain and update their health information online), and 15% indicated that if information was to be shared with others – including insurers - there would be information that they would not share with their doctor.[42] A Canadian public opinion survey conducted in 2012 found that 52% of respondents were deemed to be very concerned about access to genetic test information, while 20% showed little or no concern. Those with the greatest concerns about privacy in general were more likely to be concerned about the specific disclosure of genetic test results, as were older respondents and those with higher levels of education.[43] Importantly, this study examined terms of disclosure of genetic test results for non-health purposes – which included insurance and employment – making it difficult to elicit specific concerns regarding insurance access. However, it is consistent with a prior survey conducted in 2011 that found 86% of the sampled population were concerned or somewhat concerned about being required to provide genetic test results to an insurance company when applying for life insurance.[44]

In the US, researchers have found that participants are, in general, more willing to share health information with the state/local public health department than they are with an out-of-hospital care provider.[45] In a study of the Canadian public, Moher and El Emam reported differences in the disclosure of sensitive medical information depending on whether participants were informed that the study was conducted by a publicly-funded, university-affiliated research group or a (fictitious) privately-funded research company.[46] In a US study, Grande *et al*, found that participants were more willing to share electronic health information with university hospitals than they were with public health departments or drug companies.[47] Indeed, both the use of data, and the user of this data, were deemed more important than the type of medical information being shared, even when this included the sharing of a genetic test result.[47] In a Canadian study

of consent for biobanks, both the individual who would benefit from the research and research focus were found to have greater importance for decision making than details of privacy or confidentiality.[48] These studies suggest that the user of the information and objectives of the research do influence participant willingness to share information, irrespective of how the information is generated. Moreover, the type of information being shared also appears to play a role in determining the willingness to share information, with one study reporting that participants were more concerned about sharing information about mental illness than they were about sharing information about genetic disorders (categorized generally).[45] The potential combined impact of tested condition, status of user and study objectives on willingness to share information in the context of genetic testing and insurance has not been examined empirically.

The Canadian situation

At the national level there is currently no Canadian legislation that explicitly prohibits genetic discrimination or access to genetic data for the purposes of underwriting by life insurers.[20] However, an individual with a genetic predisposition could be protected to a limited extent in a context involving the federal government by existing human rights law such as the *Canadian Human Rights Act* (art. 3)[49] or the *Canadian Charter of Rights and Freedoms*.[50] The *Tri-Council Policy Statement* (2010),[51] a prominent national research ethics document, considers the risk of genetic discrimination to individuals participating in genetic research and recognizes that equal treatment and risk disclosure is fundamental in research. The Canadian Life and Health Insurance Association has adopted a *Position Statement on Genetic Testing* (last revised in 2010 and currently under review). According to this guideline, members will not impose genetic testing on insurance applicants but if tests have already been conducted and the information is available to the applicant and/or the applicant's physician, the insurer can request access to that information just as it would for other aspects of the applicant's health history.[10]

While the debate about the protection of genetic information from third parties is longstanding, it was only after the adoption of GINA and the strong lobbying of the Huntington Society that Canada saw its first legal proposition to address this issue. In April 2010, *bill C-508* was introduced to amend the *Canadian Human Rights Act* in order to protect Canadians from discrimination on the basis of their genetic characteristics. During the same session, *bill C-536* was also introduced to add the term 'genetic characteristics' to the list of prohibitive grounds of discrimination in the *Canadian Human Rights Act*. These are both private members' bills that are unlikely to pass due to the limited attention and low approval rates for private bills. Recently, *bill S-218* has been proposed to prohibit the act of forcing a person to undergo a genetic test or to communicate a genetic test result in order to enter or maintain a contract. It has now passed the stage of second reading as S-201. If adopted, S-201 would modify the *Canada Labour Code* and the *Canadian Human Rights Act* to prevent insurers and employers from using genetic test results. However the adoption of S-201 could raise important constitutional issues given that private personal insurance is generally considered a provincial competency field. More recently in the province of Ontario, a Private Member's Bill has been introduced by MPP Michael Colle on November 4th 2013 entitled the *Human Rights Code Amendment Act (Genetic Characteristics), 2013* (bill 127).[52] If passed, this bill would amend Ontario's Human Rights Code to include 'genetic characteristics' as prohibited grounds for discrimination. Should such legislation be enacted in Ontario it may influence other provinces to follow suit.

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Conclusions

While arguments have been advanced on the negative impact of the disclosure of genetic information for life insurance underwriting, empirical research regarding the realities of insurance discrimination in this field remain equivocal. Thus, despite the debate, the empirical evidence is often anecdotal, inconclusive or suffers from substantial methodological issues. For example, studies of experiences with discrimination often only consider those affected by genetic conditions or focus solely on the question of insurance following a genetic test. There is a tremendous need for comparative research to explore whether concerns over genetic information are extensions of more general concerns over access to personal medical information. Do individuals with non-genetic, but highly stigmatized conditions also face discrimination for life insurance or in other spheres of life? Do people share similar concerns about disclosing genetic testing information as they do other types of medical information, such as a family history of mental illness? These questions have received worryingly little consideration in North America, and given the expansion of genomic technology and increased abilities to explore the genomic influences of common complex disorders, the need for answers is pressing. The importance of this lies not only in the context of academia or law, but also health: could a perceived failure to appropriately protect medical information negatively impact on healthcare utilization? Given recent technological advances that provide unprecedented abilities to explore individual genetic and genomic information, and the increasing advocacy for special measures to protect genetic information, there is a need for renewed debate and analysis regarding the potential for genetic discrimination within the context of life insurance underwriting and a constructive discourse regarding appropriate legislation in Canada.

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