Centre of Genomics and Policy
Centre de génomique et politiques

McGill

Submission to the Standing Senate Committee on Human Rights regarding Bill S-201, *An Act to prohibit and prevent genetic discrimination*

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About the Centre of Genomics and Policy

The Centre of Genomics and Policy (CGP) of McGill University welcomes the opportunity to present this brief to the Standing Committee on Human Rights regarding Bill S-201, *An Act to prohibit and prevent genetic discrimination.*

Established in 2009, the CGP is at the crossroads of the legal, medical and public policy fields. The CGP consists of researchers, research assistants and academic associates with multidisciplinary expertise in law, ethics, sociology and medical sciences. The CGP promotes prospective structuring and guidance in both genomic health sciences and its applications. With a multidisciplinary perspective and in collaboration with national and international partners, the CGP analyzes socio-ethical and legal norms influencing multiple aspects of the promotion, prevention and protection of human health.

The CGP is internationally recognized for its expertise in research and policy on genetic discrimination. In 1991, founding member Bartha M. Knoppers conducted the first Canadian review of genetic discrimination for the Law Reform Commission of Canada.[1] In 2004, the CGP was responsible for the creation and scientific leadership of the Canadian Task Force on Genetics and Life Insurance[2]. Most recently, in 2013, Research Director Yann Joly and colleagues published the first systematic review of the existing studies on genetic discrimination.[3] The CGP continues to pioneer research on this subject.[4]

We appreciate the opportunity to comment on Bill S-201 and to draw the attention of the Committee to certain elements that are relevant from the legal, ethical and public health perspectives. We would welcome the opportunity to appear before the Committee and present on the topics covered in our submission, which was prepared by Ida Ngueng Feze Esq., Lingqiao Song, Prof. Yann Joly and Prof. Bartha M. Knoppers.

Submissions

1. Advances in medical research have generated a greater understanding of diseases and facilitated the development of new methods for their prevention, screening and treatment.[5] Through this process, an unprecedented amount of genetic information is being generated from genetic test results conducted in both clinical and research settings. The increasing availability of this genetic information has raised some concerns about its use outside of the therapeutic context.[6] Although there is currently a lack of evidence of the existence of systemic discrimination based on genetic information in Canada (except in the specific context of Huntington's disease[7]), patient groups, professional associations and government bodies have expressed concerns about possible discrimination risks.[8]

2. The Centre of Genomics and Policy of McGill University welcomes the opportunity to bring to the attention of the Committee the following points:

I. The CGP supports the adoption of a prohibition on genetic testing of individuals as a condition for accessing goods and services.

3. The Centre remains in support of the position of *Bill S-201* to prohibit genetic testing from being required as a condition for accessing goods or services. Imposing genetic testing on individuals goes against fundamental principles of Canadian society such as respect for human dignity and individual autonomy.

II. The current version of *Bill S-201* no longer suffers from the constitutional limitations identified in the previous version of the Bill.

4. The present version of *Bill S-201* does not raise the constitutional challenges identified in our previous Submission (dated June 9th 2014) because it no longer explicitly infringes upon provincial fields of competence. However, it should be noted that the areas in which cases of genetic discrimination (GD) are most likely to manifest remain situated within provincial fields of competence (e.g. private contracts including insurance and employment outside of the government sector, education, adoption, etc.) and therefore the impact of the current *Bill S-201* will mostly be symbolic.

5. Nevertheless, the protection provided by *Bill S-201*, even though limited to federal jurisdiction, could help provide momentum for the adoption of complementary legislation by provincial policymakers to more thoroughly protect Canadians from genetic discrimination.

III. Given the limited data on the impact of genetic discrimination and on the best methods of addressing this phenomenon, additional research initiatives should be encouraged.

6. To date, there has been no convincing evidence from researchers or patient groups to demonstrate the existence of GD in complex, multi-factorial diseases involving genetic susceptibilities or in personalized healthcare.[9] Given the lack of evidence for GD outside of Huntington's disease, and the challenge of coming up with a definition of genetic testing that is both scientifically sound and convenient to implement, it should be recognized that the problem may not be the actual existence of GD in Canada so much as the misperception that such discrimination is occurring. In this case, it remains to be determined whether a legal response is the appropriate way of appeasing popular anxiety on this matter.

7. We have recently completed a study of over 50 American, European and Asian countries that have adopted legislation or policies addressing genetic discrimination. From our preliminary findings (presently unpublished), we note that some studies show that concerns about GD have remained in some countries where legislation has been adopted. These results raise questions about the adequacy of a purely legal solution to this problem. Our preliminary data suggests that we also consider additional approaches, such as educating various stakeholders on the predictive limits of genetic test results for most common diseases and on the importance of avoiding genetic essentialism, as well as the need for the provinces to ensure access to a minimum amount of life insurance to all Canadians independent of health status.

8. We propose that the Standing Senate Committee on Human Rights recommend the creation of an official Task Force composed of a multi-disciplinary pan-Canadian group of experts (researchers from different provinces, insurance representatives, actuaries, health professionals etc.) who would be entrusted with monitoring not just the incidence of GD but also the fears associated with it. This Task Force would document the impact of the proposed *Bill S-201*, keep a record of Canadian studies and legal complaints on the subject of GD, and serve as a platform for the exchange of best practices between provinces. Several Canadian stakeholders (ex. CLHIA, Huntington Society of Canada, Office of the Privacy Commissioner of Canada, etc.) have already been involved in such work for a number of years and this initiative could serve as a vehicle for a more integrated national approach to this issue. The Task Force could be constituted for a specific, mandated renewable period.

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[1] Bartha Maria Knoppers, *Human dignity and genetic heritage* (Ottawa: Law Reform Commission of Canada, 1991).
[2] Bartha M. Knoppers and Yann Joly, "Physicians, genetics and life insurance" Canadian Medical Association Journal (2004) 170(9), pp. 1421-1423.
[3] Yann Joly, Ida Ngueng Feze and Jacques Simard, "Genetic discrimination and life insurance: a systematic review of the evidence" (2013) BMC Medicine 11:25.
[4] Our most recent studies since the publication of our systematic review include: Ida Ngueng Feze, Shahad Salman, Yann Joly, «Implications for health and life insurances and other legal aspects of genetic testing» In Schneider & Bras (eds.), *Movement Disorder Genetics*, Springer 2015; Shahad Salman, Ida Ngueng Feze, Yann Joly (2015) "La divulgation de l'information génétique en assurances" 93:2 Canadian Bar Review 501; Michele Lane, Ida Ngueng Feze, Yann Joly, (2015) "Genetics and personal insurance: perspectives of Canadian cancer genetic counselors" The Journal of Genetic Counselors 24(6): 1022-1036; DOI 10.1007/s10897-015-9841-9 (open access); Yann Joly, J. Rosel Kim, Shahad Salman, Ida Ngueng Feze, "The use of genetic information outside of the therapeutic or health research relationship: an international perspective" In Gerard Quinn, Aisling De Paor and Peter Blanck (eds.), *Genetic Discrimination: Translatlantic Perspectives on the Case for a European Level Legal Response*. New York: Routledge, 2014; Ida Ngueng Feze and Yann Joly, "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" (2014) Current Pharmacogenomics and personalized Medicine 12(1):56-64; and Yann Joly, Hilary Burton, Bartha M Knoppers, Ida Ngueng Feze, Tom Dent, Nora Pashayan, Susmita Chowdhury, William Foulkes, Alison Hall, Pavel Hamet, Nick

Kirwan, Angus Macdonald, Jacques Simard and Ine Van Hoyweghen (2013) "Life insurance, risk stratification and personalized medicine" European Journal of Human Genetics doi:10.1038/ejhg.2013.228.

[5] Yann Joly, Maria Braker and Michael Le Huynh, "Genetic discrimination in private insurance: global perspectives" (2010) New Genetics and Society 29(4), pp. 351-368.

[6] Yann Joly, Hilary Burton, Bartha Maria Knoppers et al, "Life insurance: genomic stratification and risk classification" (2014) European Journal of Human Genetics 22, pp. 575-579.

[7] Yvonne Bombard, Elizabeth Penziner, Joji Decolongon et al, "Managing genetic discrimination: strategies used by individuals found to have the Huntington disease mutation" (2007) Clinical Genetics 71, pp. 220-31; Yvonne Bombard, Elizabeth Penziner, Oksana Suchowersky et al, "Engagement with genetic discrimination: concerns and experiences in the context of Huntington disease" (2008) European Journal of Human Genetics 16, pp. 279-89; Yvonne Bombard, JoAnne Palin, Jan M. Friedman et al, "Beyond the patient: the broader impact of genetic discrimination among individuals at risk of Huntington disease" (2012) American Journal of Human Genetics 159(B), pp. 217-26.

[8] Joly (2013), *supra* note 3.

[9] Joly (2013), *supra* note 3.