

Revisiting Genetic Discrimination
Issues in 2010:
Policy Options for Canada

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1992

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Discrimination as a Consequence of Genetic Testing

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Summary

Genetic discrimination refers to discrimination directed against an individual or family based solely on an apparent or perceived genetic variation from the “normal” human genotype. We describe here the results of a case history study designed to assess whether or not genetic discrimination exists. Using the above definition of genetic discrimination and applying stringent criteria for case selection, we find that genetic discrimination exists and is manifested in many social institutions, especially in the health and life insurance industries. Stigmatization, and denial of services or entitlements to individuals who have a genetic diagnosis

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FOREWORD: GENETIC EXCEPTIONALISM

Glenn McGee

Collected on the occasion of the *Harvard Journal of Law & Technology's* Symposium on "Privacy, Property, and Family in the Age of Genetic Testing," the articles in this issue of the *Journal* sketch the landscape of contemporary genetic and reproductive law and policy.

What Makes Genetic Discrimination Exceptional?

Deborah Hellman[†]

I. INTRODUCTION

Recent advances in understanding the genetic basis of disease has inspired hope but also fear. While establishing a link between a person's genetic makeup and a propensity to disease may lead to better treatment, many scientists, physicians, and

Is genetic information relevantly different from other kinds of non-genetic information in the life insurance context?

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ABSTRACT

Within the medical, legal and bioethical literature, there has been an increasing concern that the information derived from genetic tests may be used to unfairly discriminate against individuals seeking various kinds of insurance; particularly health and life insurance. Consumer groups, the general public and those with genetic conditions have also expressed these concerns, specifically in the context of life insurance.

While it is true that all insurance companies may have an interest in the information obtained from genetic tests, life insurers potentially have a very strong incentive to (want to) use genetic information to rate applicants, as individuals generally purchase their own cover and may want to take out very large policies.

This paper critically focuses on genetic information in the context of life insurance. We consider whether genetic information differs in any relevant way from other kinds of non-genetic information required by and disclosed to life insurance companies by potential clients. We will argue that genetic information should not be treated any differently from other types of health information already collected from those wishing to purchase life insurance cover.

Individuals purchase insurance as a precaution against costly unpredictable events.

The purpose of insurance generally is to spread the costs of very expensive but unpredictable events across a similar group of insured individuals. Insurers are in the business of risk assessment and discrimination. Individuals seeking insurance are categorised into groups on the basis of certain factors, some of which they have no control over, and insurance companies set their premiums depending on the statistical likelihood that groups will go onto to make claims on their insurance policies.³ The measures insurers put in place to differentiate between people underlie the underwriting process.

All insurers, regardless of the type of insurance being offered, generally require detailed information from applicants in order to assess their risk (and hence their attractiveness or suitability to insure).

Life insurance differs from many other types of insurance available because one's health status is central to whether insurance is offered, and under what conditions. That is, the past and present

CGAT—Canadian Genetic Analysis and Technology Program (1992-1995)

- Partnership between Industry Canada and major research funders (NCI, MRC, NSERC, SSHRC)
- Significant funding allocated to examine ELSI issues associated with expanding knowledge of genetics

Forward: The CGAT-MELSI Program

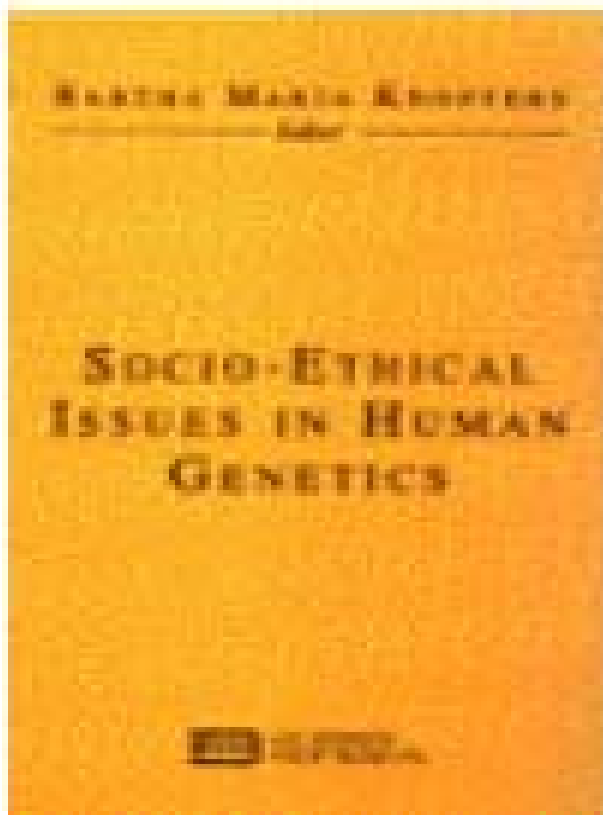
The Canadian Genome Analysis and Technology Program (CGAT) was formed in 1992 as a component of the International Human Genome Project. The major partner was Industry Canada but the other partners included the Medical Research Council (MRC), the National Cancer Institute of Canada (NCIC), the Natural Sciences and Engineering Research Council of Canada (NSERC) and the Social Sciences and Humanities Research Council of Canada (SSHRC). MRC took the leadership role in management. Canada's program specified that at least 7.5% of funds provided be spent for research into the ethical, legal and social implications (MELSI) of the expanded knowledge of genetics. Grants were also provided to support conferences, workshops and symposia held within Canada, and for travel to attend scientific meetings related to genome research. CGAT ended in April 1997.

The objectives of CGAT were to:

- build on existing strengths to create new capabilities in genomics that will enhance and maintain Canada's international position;
- coordinate Canadian genome research to achieve a critical mass of effort, with a focus on genetic mapping and sequencing, technology development, information management, and analysis of social, ethical and legal issues;
- direct resources to areas of research that complement the activities of the international human genome project, and avoid overlap in Canada;
- train a new generation of researchers, knowledgeable in the field of genomics and genetic analysis, and developing expertise on social, ethical and legal aspects;
- respond to Canadian health, social and industrial interests;
- facilitate access by Canadian industry to both domestic and international genome research plans and findings.

The CGAT MELSI Advisory Committee was established in the fall of 1993. The mandate and general strategy adopted by the members were as follows:

Bartha Maria Knoppers (ed.)



Genetics in Life, Disability and Additional Health Insurance in Canada: A Comparative Legal and Ethical Analysis

Trudo Lemmens and Poupak Bahamin

Executive Summary

The development of genetic testing is likely to spur the interest of insurance companies. Genetic tests aim at detecting genetic mutations that indicate the risk of disease. Insurers traditionally differentiate people according to their risks. For the purpose of risk analysis and classification (underwriting), they usually request access to information already present in medical records and sometimes ask applicants to undergo new medical tests. Genetic tests or genetic information can often be useful for underwriting.

Practical and ethical problems arise with genetic testing. First, even with genetic testing, accurate prediction remains difficult and depends on the disease and the availability of tests (1.2). Some single-gene disorders, such as Huntington's, are more "determinant" than others. Most diseases, however, are caused by an interaction of genes, environmental, cultural and socio-economic factors (1.2.1-1.2.2). Tests for susceptibilities indicate only an increased risk for disease and say nothing about actual health. This risk can sometimes be decreased by an appropriate diet, a change of lifestyle, or by other preventive measures. The sensitivity and specificity of tests, moreover, vary widely (1.3.1). Likewise, presymptomatic testing for late-onset disorders cannot predict the actual age of onset, the severity, or even the certainty that a disease will be expressed. Thus, phenomena such as variable expressivity, incomplete penetrance, and heterogeneity hinder clear prediction (1.2.3).

In addition to general ethical problems associated with the application of new technologies in medicine, specific problems arise with genetic testing (1.3). After being tested, people might be stigmatized as ill without actually having any symptoms. Genetic information on individuals, moreover, has an impact on families and on ethnic or religious groups. Some genetic tests reveal susceptibilities to diseases that can be prevented or controlled through changes in diet, lifestyle, or with appropriate medication. The absence of treatment or of a cure makes other genetic information particularly cumbersome. Using genetic information outside the medical context, to exclude people from services or opportunities available to others, could affect their willingness to participate in genetic research. Although

Physicians, genetics and life insurance

Bartha M. Knoppers, Yann Joly

Should women who come from at-risk families get life insurance before being tested for genetic susceptibility to breast cancer? Should physicians warn patients who request a genetic test to get life insurance first? How should physicians react to requests from insurance companies for genetic information about their patients?

There are no definitive answers to questions such as these. However, a 2003 public opinion survey¹ revealed that the wide majority of Canadians reject the idea that insurance companies have the right to ask for genetic information even if applicants have personal knowledge of this information. Indeed, the international debate surrounding the role of life insurance, the necessity of risk rating and the notion of "acceptable discrimination" has raised questions about the larger social role of insurance. This debate has been polarized by recent developments in the field of genetics that, in theory, would allow insurers to make use of genetic testing technology as a new underwriting tool.

The importance of genetic information has grown exponentially in the last 20 years. Since the Law Reform Commission of Canada first raised the issue of "insurance testing" in 1991, scientists have completed a draft of the human genome and have identified more than 2 million single nucleotide polymorphisms.² The number of predictive genetic tests offered for monogenic and complex (multifactorial) diseases has multiplied. Nevertheless, only a small portion of the therapeutic possibilities offered by genetics has been realized.

In the United States, the genetics and insurance debate has focused predominantly on access to health insurance. Canada, like most European countries, has a uni-

history of the debate on genetics and life insurance in Canada and the reasons why a Canadian task force decided to take up the challenge.

Life insurance

Life insurance should be distinguished from social security, disability insurance, unemployment insurance, the Canadian Pension Plan and the principle of universality underlying Canada's health care system. Life insurance is a private contract between the policy-holder and the insurer. Its principal role is to provide income security to the beneficiary in the event of the insured's death.

To calculate the amount of the premium, the insurer uses information such as age, sex, health status and lifestyle as well as some information on the medical history of the insured's family. According to the principle of mutuality underlying insurance, an insured person will then be assigned to a group with similar risk factors. By its very nature, the process of underwriting discriminates between individuals³ to pool them into at-risk groups.^{3b} Unbeknownst to most, 90% of life insurance applicants are insured at standard rates.⁷

Is genetic information different from medical information?

Genetic information may alter one's perception of future medical risk. It can affect choices regarding the purchase of life insurance and the premiums to be paid.⁸ Because of the sensitive, personal, familial and social nature of genetic information, its confidentiality is essential.^{3a} At



Genetic Information and the Law

Issues in the Insurance
and Employment Settings:
A Report

4th Health Law Day
May 20, 2005





Consent, Privacy & Research Biobanks

Policy Brief No. 1

Editor's Preface

GPS: Where Genomics, Public Policy and Society Meet is an Ottawa GEPLS Series led by Genome Canada to bring together leading researchers and senior federal policy-makers to explore options for addressing public policy issues at the interface of genomics and society. The resulting "Policy Directions Briefs" present the evidence base needed to support informed debate on a range of policy options, while deliberately stopping short of making any recommendations. Topics are selected on the basis of their broad societal importance, national interest, relevance to federal policy-makers, and "ripeness" for policy uptake.

Co-authors of the Policy Briefs are renowned leaders in the field, commissioned by Genome Canada to synthesize the current state of academic knowledge on a given topic and translate it into a format and language familiar to senior federal policy makers. Co-authors are asked to present a well-balanced range of feasible policy options, as neutrally as possible, and avoid favoring any particular position over another. The Policy Brief is not intended to reflect the authors' own views or opinions, nor those of Genome Canada.

The co-authors have benefited from valuable

Authors:

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26 January 2010

Executive Summary

In March 2009, Time Magazine picked biobanking as one of the TOP 10 Ideas changing the world right now. Indeed, large biobanks, linked with health, demographic and administrative data, are proliferating in countries around the world, not least of which is Canada. Scientists are poised internationally with an unprecedented ability to tease out complex interactions between genes and environment, enhancing our understanding of health and disease and paving the way towards a future of personalized medicine and public health. Meanwhile, existing legal and policy frameworks for personal data protection are founded on the concept of informed consent, the application of which has proven to be challenging for advancing biobank research and related scientific progress in Canada. This Policy Brief explores three possible policy options for implementing the concept of consent in the context of research biobanks: 1) specific and fully informed consent for each project; 2) broad initial consent accompanied by appropriate governance; and 3) opt-out model. The types of research biobanks being contemplated include: large population-based biobanks, disease-specific biobanks and biobanks created from left-over archival tissue originally collected in the context of clinical care.



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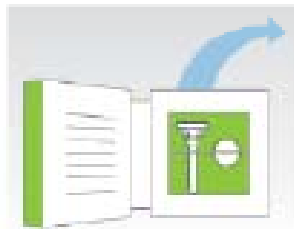
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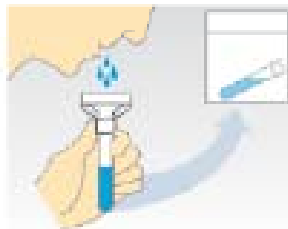
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- How accurate is the genetic data you provide?
- Which countries do you ship to?
- How can I give the personal genome service as a gift?
- What is 23andMe's return policy?

Genetics 101

23andMe provides a collection of education materials to guide you on your personal journey of genetic discovery. Explore our learning resources and



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Our Technology and Standards

23andMe is a retail DNA testing service providing information and tools for consumers to learn about and explore their DNA. We utilize the Illumina Infinium HumanHap650-Quad HD Bead Research Use Only Chip which has been customized for use in all of our products and services by 23andMe. All of the laboratory testing for 23andMe is done in a CLIA-certified laboratory.

Technical Support and Resources

AUTOS

THE DNA AGE; Fear of Insurance Trouble Leads Many to Shun or Hide DNA Tests

By AMY HARMON
Published: February 24, 2008

PHOTOS: Katherine Anderson, seen in a checkup last week, found a blood clot last year partly due to an undiagnosed genetic condition.(PHOTOGRAPH BY BRENDAN SMIALOWSKI FOR THE NEW YORK TIMES); Victoria Grove sometimes wears a mask against infection, knowing its added danger for her.(PHOTOGRAPH BY BEN GARVIN FOR THE NEW YORK TIMES)(pg. A25)

Employers say discrimination is already prohibited in the workplace by the Americans with Disabilities Act and existing laws governing privacy of medical records. But employee rights advocates say nothing in those laws explicitly prevents employers hard-pressed to pay for mounting health care costs from trying to screen out employees they know are more likely to get sick.

Courts have yet to rule on the subject. When the Equal Employment Opportunities Commission sued the Burlington Northern Santa Fe Railway for secretly testing the blood of employees who had filed compensation claims for carpal-tunnel syndrome in an effort to discover a genetic cause for the symptoms, the case was settled out of court in 2002.

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One Hundred Tenth Congress
of the
United States of America

AT THE SECOND SESSION

*Begun and held at the City of Washington on Thursday,
the third day of January, two thousand and eight*

An Act

To prohibit discrimination on the basis of genetic information with respect to health insurance and employment.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE; TABLE OF CONTENTS.

(a) **SHORT TITLE.**—This Act may be cited as the “Genetic Information Nondiscrimination Act of 2008”.

(b) **TABLE OF CONTENTS.**—The table of contents of this Act is as follows:

- Sec. 1. Short title; table of contents.
- Sec. 2. Findings.

TITLE I—GENETIC NONDISCRIMINATION IN HEALTH INSURANCE

- Sec. 101. Amendments to Employee Retirement Income Security Act of 1974.
- Sec. 102. Amendments to the Public Health Service Act.
- Sec. 103. Amendments to the Internal Revenue Code of 1986.
- Sec. 104. Amendments to title XVIII of the Social Security Act relating to medigap.
- Sec. 105. Privacy and confidentiality.
- Sec. 106. Assuring coordination.

TITLE II—PROHIBITING EMPLOYMENT DISCRIMINATION ON THE BASIS OF GENETIC INFORMATION

- Sec. 201. Definitions.
- Sec. 202. Employer practices.
- Sec. 203. Employment agency practices.

Genetic Information
Nondiscrimination Act of
2008

Perceptions of genetic discrimination among people at risk for Huntington's disease: a cross sectional survey

Yvonne Bombard, postdoctoral fellow,^{1,5} Gerry Veenstra, associate professor,² Jan M Friedman, professor,¹ Susan Creighton, genetic counsellor and clinical assistant professor,¹ Lauren Currie, research assistant,¹ Jane S Paulsen, professor,³ Joan L Bottoff, professor and director,⁴ Michael R Hayden, Canada Research chair in Human Genetics and Molecular Medicine, University Killam professor¹ the Canadian Respond-HD Collaborative Research Group

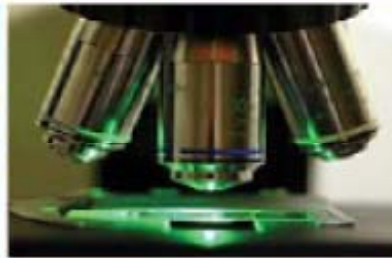
¹Department of Medical Genetics, University of British Columbia, Vancouver, BC, V5Z 4H4, Canada (institution where the research was conducted)

²Department of Sociology,

ABSTRACT

Objective To assess the nature and prevalence of genetic discrimination experienced by people at risk for Huntington's disease who had undergone genetic testing or remained untested.

discrimination.^{1,4} Genetic discrimination refers to the perceived unfair treatment of individuals or their family members based on presumed or actual genetic differences as opposed to physical features.⁵ Fear of genetic discrimination has prevented individuals



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Canada considers genetic discrimination law

01 March 2010

By *MacKenna Roberts*

Appeared in BioNews 547

Canadians need better protection from genetic discrimination by insurers and employers, according to Winnipeg North MP Judy Wasylycia-Leis.

Mrs Wasylycia-Leis announced she will introduce a proposal into the Canadian House of Commons this spring amending the Human Rights Act to include 'genetic characteristics' as a prohibited ground for discrimination.

'This bill will stop Canadians' personal genetic information from being used against them', she

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Department
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Keeping the GINA in the bottle: assessing the current need for genetic non-discrimination legislation in Canada

DARYL PULLMAN, TRUDO LEMMENS

Daryl Pullman, PhD, is Professor of Medical Ethics in the Faculty of Medicine, Memorial University, St. John's, NL, Canada. **Trudo Lemmens**, LicJur, LLM (bioethics), DCL, is Associate Professor in the faculties of Law and Medicine, University of Toronto, Toronto, Ont., Canada.

Competing interests: None declared.

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Rapid advances in genetic science and technology have led to the wide availability of genetic testing for a broad range of conditions. The compan-

Such a high level of legislative activity indicates a deep and abiding public concern about the issue of genetic discrimination. Yet the same level of angst has yet to make its way north. Although a recent Canadian study reports on perceptions of genetic discrimination with regard to people at risk for Huntington's disease,² discussion of the general issue in Canada has been limited and is focused primarily on discrimination in the context of life insurance.⁴ More significantly, there is no legislation comparable to GINA at either the federal or the provincial/territorial level in Canada. Does the absence of such legislation mean that Canadians are at higher risk of genetic discrimination than Americans? Does Canada require similar legislation?

The US experience

Despite widespread concern in the United States about discrimination on the basis of genetic test results, there were few documented examples of its occurrence, and no evidence that genetic testing for employment or health insurance purposes was common.^{4,5} Greely⁶ maintains that market conditions were such that there was relatively little incentive for insurers to use genetic testing to discriminate. Before pursuing such a course, an insurer would need to be confident that the financial benefits of introducing genetic testing to differentiate people would significantly outweigh the costs. As for employers, the potential costs of negative publicity, employee dissatisfaction, and resulting litigation would be significant if it

Policy Option 1: Human Rights Legislation

European Convention Human Rights and Biomedicine

- Prohibition to Discriminate on Basis of Genetic Heritage (art. 11)
- Genetic Testing only for “health purposes” or scientific research for health purposes, and subject to genetic counselling (art. 12)
- Signed by 34, ratified by 26 member states Council of Europe (including Czech Republic, Croatia, Finland, Hungary, Norway, Portugal, Spain, Switzerland, Turkey)

Human Rights Based Legislation

- Genetic-Specific Provisions in H.R. type legislation: e.g. Germany, Ireland, Switzerland, South Korea, France (including in Code Civil), Estonia (Human Genome Research Act)
- Provisions in specific legislation insurance: Austria, Belgium, Denmark, Lithuania, Luxembourg, Norway, France

United States

- GINA
- States: Genetic-specific discrimination statutes:
 - Health Insurance: 45 States
 - Employment: 35 States
 - Life insurance: 14 States
 - Disability Insurance: 15 States
 - Long-Term Care Insurance: 9 States
 - Note: variable provisions
 - **E.g. 8 States require actuarial justification for use of genetic information in insurance**

Human Rights Law Canada

- Canadian Charter
- Canadian Human Rights Act
- Provincial Human Rights Acts


Discrimination Provisions

- General: Prohibition to discriminate on the basis of “enumerated and analogous grounds”: age, sex, health, disability, sexual orientation, marital & family status, ...
- Exceptions for distinctions that are “*reasonable and bona fide.*”

Genetics and Discrimination Standard

- Genetics: Disability
- Other prohibited grounds?
 - Race and Ethnicity
 - Ancestry (Ontario Human Rights Code)
 - Age, Sex, Sexual Orientation

Human Rights Options Canada (1): Add prohibited ground: 'Genetic information', 'genetic trait', 'genetic heritage', 'genetic characteristic' or 'future health risk'

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	3rd Session, 40th Parliament, 59 Elizabeth II, 2010	3 ^e session, 40 ^e législature, 59 Elizabeth II, 2010	
	HOUSE OF COMMONS OF CANADA	CHAMBRE DES COMMUNES DU CANADA	
	BILL C-508	PROJET DE LOI C-508	
	An Act to amend the Canadian Human Rights Act (genetic characteristics)	Loi modifiant la Loi canadienne sur les droits de la personne (caractéristiques génétiques)	
R.S., c. H-6	Her Majesty, by and with the advice and consent of the Senate and House of Commons of Canada, enacts as follows:	Sa Majesté, sur l'avis et avec le consentement du Sénat et de la Chambre des communes du Canada, édicte :	L.R., ch. H-6
	1. Subsection 3(1) of the <i>Canadian Human Rights Act</i> is replaced by the following:	1. Le paragraphe 3(1) de la <i>Loi canadienne sur les droits de la personne</i> est remplacé par ce qui suit :	
Prohibited grounds of discrimination	3. (1) For all purposes of this Act, the prohibited grounds of discrimination are race, national or ethnic origin, colour, religion, age, sex, sexual orientation, <u>genetic characteristics</u>, marital status, family status, disability and conviction for which a pardon has been granted.	3. (1) Pour l'application de la présente loi, les motifs de distinction illicite sont ceux qui sont fondés sur la race, l'origine nationale ou ethnique, la couleur, la religion, l'âge, le sexe, l'orientation sexuelle, <u>les caractéristiques génétiques</u>, l'état matrimonial, la situation de famille, l'état de personne graciée ou la déficience.	Motifs de distinction illicite

Genetics and Bona Fide Justifications (BFJ)

1. Rational connection between the requirement and a **legitimate purpose**

– Employment

- Occupational health and safety
- Public safety
- Workplace qualifications?

– Insurance: underwriting and risk assessment

Genetics & BFJ

2. **Duty to Accommodate** unless undue hardship

Undue Hardship:

- Excessive costs
- Impact on others
- Possible alternatives?
- Have others fulfilled their obligation?
- Is individual assessment possible?
- Scientific & evidentiary basis of a test: important but not sufficient

Human Rights Options Canada (2)

- Regulations Specifying BFJ or Undue Hardship
- Development of Interpretative Guidelines by HRCs
- Prior Review of BFJ by HRCs (model: NB, NS, NF&L)

Policy Option 2: Privacy Legislation

Int'l Examples Privacy Statutes

- **Australia** – amendment Privacy Act 2006
 - *health information* includes: genetic information ...
 - *sensitive information* includes: genetic information about an individual that is not otherwise health information
- **Estonia**: 'sensitive personal data' includes 'genetic info' in Personal Data Protection Act
- **US**: 27 States have Statutory Provisions on Privacy of Genetic Data

Stringent Prohibition in Privacy Statutes:

- **Poland & Portugal**: Personal Data Protection Acts: 'Processing' of personal data revealing genetic information prohibited

Relevant Principles of Privacy Statutes

- Consent Principle: refusal of consent for storage of information cannot be a ground to refuse a service
- Reasonable purpose & proportionality: collection, storage and use only as much as necessary for reasonable purpose; use only in line with purpose of original collection
- Quality of data

Privacy Options Canada

- Interpretative Guidelines by Privacy Commissions on 'reasonable purpose', 'proportionality', 'storage' re genetic info
- Statutory provisions on genetic information and on 'shared' privacy interests individuals & genetic relatives

Policy Option 3: Comprehensive Regulatory Review System

Regulatory Framework including Review and Approval System

- Quality, effectiveness, and informational risk assessment
 - WHO can perform test?
 - WHO can have access to test results?
 - WHAT form of testing?
 - WHY: For What Purpose?

Example: Germany Draft Human Genetic Examination Act

- Prohibition Genetic Discrimination
- Regulation of Use of Genetic Testing: medical and research purpose
- Genetic Diagnostic Commission: Regulatory Review
- Specific Provisions for Employment and Insurance Testing
 - Including Ceiling Approach to Insurance use of Genetic Test Results

4: Sector-Specific Policy Options

Policy Options Insurance

- Ceiling approach
 - Basic insurance, no access to genetic test results and/or no genetic testing used
 - Use of genetic information (and genetic testing) above the ceiling allowed

Changes to Insurance Law

- Level of information sharing
 - E.g.: disclosure obligation in some countries limited to reasonable responses to questionnaire of insurer
- Sanctions for non-disclosure
 - Differentiation between willful concealment of information and non-disclosure
 - France: sanction for non-disclosure in proportion to the risk that was concealed

Policy Option 5: Self-regulation by industry

- Existing 'moratorium' on testing itself
- Ombuds- and complaints system with mediation
- Possibility of development of standards for genetic testing

e.g. UK 'concordat': moratorium & ceiling approach

Practical Considerations Related to Type of Policy Intervention

- Extent of protection & omprehensiveness
- Post-factum or pre-emptive protection
- Cost & Practical Impediments to regulatory & legislative changes
- Federal-Provincial Jurisdiction & Overlapping Jurisdictions
- International Context

Practical & Policy Considerations Related to the Issue Itself

- Difficulty of defining 'genetic information'
- Possible challenges by others not as much protected as those at genetic risk
- 'Meaning' of regulating genetic testing: what 'message' does it send?
- Public Confidence